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ABSTRACT

The effects of deinstitutionalization on 110 severely to profoundly mentally retarded and 68 moderately to severely retarded children drawn from Laconia State School in New Hampshire were examined. Study objectives were to determine: (1) educational and residential consequences of deinstitutionalization; (2) the stability of community placements; (3) the direction of movement (to more or less restrictive environments) of the deinstitutionalization; and (4) the impact of federal and state special education policies on deinstitutionalized children. Study methods included interviews with parents and the community in which the children were based, review of clinical records, and case studies. Information was collected on characteristics of the children and their families, residential placement outcomes, education service outcomes, and the effects of community placement on families. A major conclusion was that deinstitutionalization of children has been enough of a success to justify its full continuation, but that the broader goal of full social integration or "communitization" has not been fully achieved. Social policy recommendations included the following: develop state-wide management information systems for previously institutionalized individuals; create mechanisms to help families make informed decisions; support policies aimed at the prevention of institutionalization; create incentives and enforce policies that encourage increased social integration in educational and residential settings; and create multiple approaches to the support of families of deinstitutionalized children. (CB)

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RAMPS ARE NOT ENOUGH

The Movement of Children with Mental Retardation from Institutional to Community-Based Care

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June, 1986

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PREFACE AND ACKNOWLEDGEMENTS

The research described in this report has occurred within a specific temporal and political context. The mid-1980s has been characterized by a continued commitment to improvement in the lives of people with developmental disabilities. This commitment has not come spontaneously or smoothly. It has taken federal and state legislation, court orders, and constant pressure from professionals and parents to redress the historical neglect of children and adults with severe handicaps.

The philosophical principles embodied in the concept of normalization and social role valorization have been manifested largely through the deinstitutionalization movement. These principles, articulated by Nirje, Wolfensberger, and others beginning in 1970, have had a profound impact on the way society perceives and responds to people with significant intellectual and physical differences. Placement in large residential institutions and in segregated schools and workplaces has declined drastically over the past 15 years. Today people with significant differences work, live, and play in local communities throughout the United States.

However, concerns linger about the degree to which such individuals work, live, and play <u>with</u> other community members. It is one thing to be a <u>participant in</u> a community, it is quite another to be a <u>member of</u> a community. Movement from institutions into communities is one very important measure of the success of laws and court orders. But the actual degree of social integration must also be assessed to determine whether or not the full intent of social policies has been achieved.

In addition, there is some evidence that social policies have swung all the way out to one end of the pendulum's arc. That is, the rapid and widespread movement of people out of institutions has begun to slow down. In some areas of Europe and the United States, more people are entering institutions than leaving them. The frequency of litigation has declined in the wake of the U.S. Supreme Court's Pennhurst decision, which fell short of guaranteeing community-based services for all disabled people. Plans to close institutions have been shelved, due in part to the well-publicized plight of homeless and exploited ex-residents of both psychiatric and mental retardation facilities.

This study documents the effects of deinstitutionalization in its heyday. It is too early to know whether this work comes at the beginning, middle, or end stages of deinstitutionalization. In any case, the study is concerned with one group of institutionalized individuals who have moved back into their home communities over the past decade and a half. Some evidence relative to social integration was also gathered, but the primary emphasis was on the types of residential and educational services received by children who left a large public institution to return to their families or to other community living arrangements. The purpose of the study was to conduct a policy analysis of federal and state special education laws and related policies affecting the lives of severely disabled children and their families. The analysis is based on an empirical investigation of the consequences of deinstitutionalization.

The report begins with a brief listing of the primary purposes, research questions, and value premises that guided our work. This is followed by a review of the history of services for children with mental

retardation in the United States and in New Hampshire, where the events documented in the report occurred. Chapters Three and Four then describe the techniques used to locate deinstitutionalized children and the methodology used to gather data about the children and their families. Chapter Five presents the characteristics of the research population, with an emphasis on the differences and similarities between those children who left the institution and those who remained there into adulthood. Family socioeconomic characteristics are also described here. Chapter Six begins the presentation of findings, with a focus on the residential placements of deinstitutionalized children. The types of placements, their relative stability, their size and structure, the types of habilitative services received during community placement, and the differences in placement outcomes over time are analyzed. Chapter Seven examines educational placements and services received, and uses many of the same variables included in the review of residential placements. Chapter Eight is concerned with the impact of deinstitutionalization on family members, especially parents and close relatives. Parents' attitudes toward deinstitutionalization and the effect of historical changes on the family's response to community placement are emphasized in this chapter. Chapter Nine summarizes the findings of the study, and provides an analysis of their meanings and implications. Finally, Chapter Ten provides a set of general policy recommendations that arise from the findings. These recommendations are based on assumptions that (a) deinstitutionalization of children will continue in the future and (b) full social integration of disabled people is a goal of our society.

Acknowledgements

There are many more people who made this study successful than could possibly be mentioned here. First and foremost, we wish to express our deepest gratitude to the 178 children and families who consented to participate in the study. They were overwhelmingly forthcoming in sharing their personal and often painful experiences in the hope that others may benefit from this knowledge. They sat through long interviews, recounted the difficult decisions made early in their children's lives, provided frank assessments of institutional and community services, and guided us to others who could cast additional light on the experiences of severely handicapped children. These others included case managers, teachers, therapists, social workers, and guardians who were always cooperative in providing information about the services received by individual children.

The people who gathered this information were absolutely vital to the project's success. In the early stages, Chris Stockman culled through files to identify the potential research population. Her careful work laid the cornerstone for subsequent data collection. Tim Sullivan continued her work for a brief period. The bulk of the data were then gathered by Barbara Fenderson and Doris Thede, whose perseverance and commitment were inspiring. They spent countless hours poring over files, tracking down people in sometimes very isolated locations, sensitively interviewing parents and other family members, and offering suggestions for improvements in our data collection instruments. Additional data collection assistance was provided by Linda Brownstein and Bing Hawes who ably continued the work of Barbara and Doris. Data

entry was supported by Michael Roth, whose expertise got us through some very complicated and frustrating situations. Acting as an anchor and highly competent presence throughout the almost three year period of the study was Priscilla Woodman, project secretary, bookkeeper, and the preparer of this manuscript. We are extremely grateful to her.

There were several key individuals in New Hampshire who gave us good advice, pointed us in the right direction, and opened doors that enabled the work to proceed. Don Shumway and Dick Lepore of the Division of Mental Health and Developmental Disabilities, as well as Pat Fair-Riedesel, were very supportive of the project and did all they could to provide us access to data sources. At Laconia State School, Jack Melton and Frank McAloon provided initial assistance in gaining access to staff and clinical records. Various members of the Community Integration Office, the Clinical Records Department, and King Building all offered very helpful advice and assistance during the gathering of individual data.

Throughout the course of the project, we were guided by the advice and discussion of a Technical Advisory Committee made up of state-level policy makers, legislators, and administrators. This group met quarterly to review our plans, suggest key questions, describe the important social and political issues bearing on the study, and recommend ways to make the study as useful and relevant as possible. A list of the Committee members follows this preface.

Finally, we want to express our appreciation to The Spencer Foundation of Chicago for providing the financial support necessary to carry out the study. Marion Faldet of the Foundation was highly supportive of the project and very understanding as we went well beyond our anticipated completion date. The focus of the study represents a new area of activity for the Foundation, and we are very grateful that they recognized the potential benefit of our findings. The conclusions and recommendations of the study are, of course, the responsibility of the principal investigator and project director, and no endorsement of the findings or recommendations by the Foundation is implied.

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June, 1986

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This report is dedicated to the memory of Nicholas Hobbs, whose intellectual spirit and deep commitment to children and families have served as a beacon in my own search for truth and understanding.

--BLM

Chapter One

Purposes of the Study

What happens to mentally retarded children who return to their home communities after living in a large public institution? This is the primary question addressed by the following report. Over the past two and one-half years, a small team of investigators from the University of New Hampshire has attempted to gather as much information as possible on the consequences of deinstitutionalization of children who have mental retardation and related disabilities. We have located 68 individuals who lived at Laconia State School and Training Center (LSS) during the 1970s and early 1980s and who left the School before their 21st birthdays. By documenting the experiences of these children during their stay at LSS, at the time they made the transition from LSS back to their local communities, and in subsequent years, we have sought to describe and analyze the impact of deinstitutionalization on children and their families.

The specific purposes and questions of our study were:

1) To determine the educational and residential consequences of moving children with mental retardation from public residential institutions into community-based care.
   a) Where did children go to live after leaving the institution?
   b) Who had responsibility for caring for these children?
   c) What were the attitudes of the families of mentally retarded children toward institutional and community care?

d) What problems were encountered when children left the institutional setting?

e) How much and what kind of education and related services did deinstitutionalized children receive?

f) What were the characteristics of deinstitutionalized children (sex, age, level of retardation, functional abilities, secondary handicaps, family circumstances, etc.)?

g) How did deinstitutionalized children differ from their age peers who remained at the institution into adulthood?

2) To assess the stability of community placements; i.e., the frequency of change in residential and educational settings.

a) After children left the institution, how often did they move from one residence to another or from one educational program to another?

b) What were the reasons for these moves?

c) How long did children remain in each residential or educational setting?

d) How many children returned to the institution after community placement? Why did these returns occur?

3) To determine the direction of movement when children change residential or educational placements, i.e., to determine whether children enter into more or less restrictive environments when they change placements.

a) What were the characteristics of the residential and educational settings in which deinstitutionalized children were placed (type and size of facility, characteristics of other participants,

location of facility, sponsorship of facility, accessibility to normal community activities, etc.)?

b) How did the characteristics of the settings in which children were initially placed differ from the characteristics of subsequent placements?

4) To determine the impact of federal and state special education policies (both statutory and judicial) on deinstitutionalized children.

a) Has there been any relationship between the experiences of deinstitutionalized children and the implementation of legislative mandates to provide a free appropriate public education to all handicapped children?

b) Have there been any differences in the experiences of children deinstitutionalized prior to and after the implementation of these mandates?

c) Have federal court orders concerning the quality of care and requirements for least restrictive settings affected deinstitutionalized children?

d) Were there any differences in the experiences of children who left the institution prior to and after the issuance of such orders?

e) Have any children been excluded altogether from participation in community programs?

f) Who has had financial responsibility for the costs of community programs?

The answers to these questions are based on data for approximately 200 variables collected for each individual included in the study. From our analysis of those answers, we tested a model of "communitization" variables. We prefer the term communitization because it suggests a process that continues to evolve after the actual placement out of the institution. We were interested not only in the initial community placement, but also in the effects of placement on the child and his or her family and in the on-going processes of adjustment, service provision, and change as the child remained in the community over a period of time.

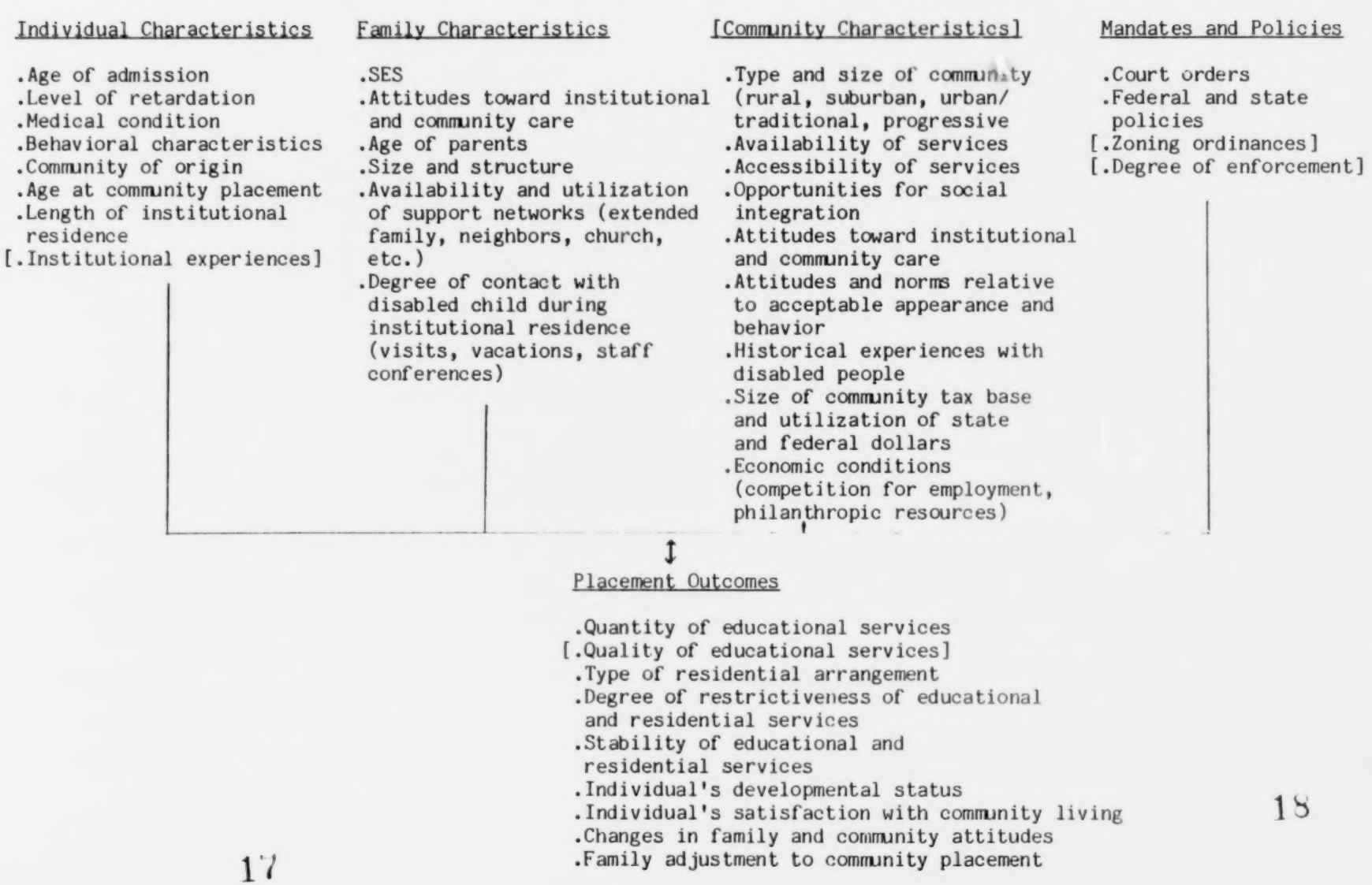
Table 1 presents a summary of the variables that we believe play a critical role in the process of the communitization of children. We have attempted to include as many of these variables as possible in the present study, given the limitations of time and money. The bracketed variables are those that we have not been able to include.

Institutional experiences were not included because (a) institutional records in the 1970s are often not complete or reliable, and (b) our primary interest was focussed on what happens after a child leaves the institution.

Community characteristics were excluded because of the tremendous time and effort necessary to gather this data. To some extent, concurrent work by James Conroy and Valerie Bradley of Temple

Table 1.1

Theoretical Model of Communitization Variables Affecting Children


Individual Characteristics
.Age of admission
.Level of retardation
.Medical condition
.Behavioral characteristics
.Community of origin
.Age at community placement
.Length of institutional residence
[.Institutional experiences]
Family Characteristics
.SES
.Attitudes toward institutional and community care
.Age of parents
.Size and structure
.Availability and utilization of support networks (extended family, neighbors, church, etc.)
.Degree of contact with disabled child during institutional residence (visits, vacations, staff conferences)
[Community Characteristics]
.Type and size of community (rural, suburban, urban/ traditional, progressive
.Availability of services
.Accessibility of services
.Opportunities for social integration
.Attitudes toward institutional and community care
.Attitudes and norms relative to acceptable appearance and behavior
.Historical experiences with disabled people
.Size of community tax base and utilization of state and federal dollars
.Economic conditions (competition for employment, philanthropic resources)
Mandates and Policies
.Court orders
.Federal and state policies
[.Zoning ordinances]
[.Degree of enforcement]
Placement Outcomes
.Quantity of educational services
[.Quality of educational services]
.Type of residential arrangement
.Degree of restrictiveness of educational and residential services
.Stability of educational and residential services
.Individual's developmental status
.Individual's satisfaction with community living
.Changes in family and community attitudes
.Family adjustment to community placement

University and Human Services Research Institute, respectively, will cast light on some of these variables as they affect mentally retarded adults. The information generated by their work in New Hampshire will complement and elaborate on our own.

Under the category of Mandates and Policies, we have not assessed the effect of zoning ordinances or the degree to which mandates are enforced. In the former case, the scarcity of group care facilities for children has meant that zoning issues have not been critical in the communitization process. Adult living facilities have drawn considerable fire in several towns in New Hampshire due to unfounded fears and lack of previous experiences with disabled people, indicating this may be a critical issue as residential programs for children are established in the future. The "degree of enforcement" variable is a subtle one that would require more field work and analysis than is in our capacity, but it is one we hope will be investigated at some point. The loftiest goals and requirements are meaningless if their implementation is not monitored and sanctions for non-compliance are not utilized.

"Quality of educational services" was not assessed in this study, again due to the limits of time and money. Because our work is an initial effort to document the experiences of children who have left a public institution, most of our work is descriptive rather than evaluative. Observation and review of specific local educational programs in which children are placed are very time consuming, labor intensive tasks. Our major purpose has been location of children and determining the overall patterns of placement and stability. Some

insight into the quality of educational services is provided in a 1985 report by AGH Associates on programs for 20 deinstitutionalized children in New Hampshire. Reference to these findings will be made in later sections.

It is important to emphasize that this report does not answer the question, "Are children better off as a result of moving from the institution back into the community?" Although that is a very critical question, lack of reliable institutional data on the children's developmental status at the time of institutional placement and throughout the period of institutional residency make it impossible to come up with a valid answer. Readers of this report may make their own inferences as to the relative value of community vs. institutional care for mentally retarded children. The data presented here, however, are not intended to provide a definitive answer as to the developmental benefits of either alternative.

The ultimate purpose of this study is to assess the impact of changing social policies on children with mental retardation. Once the impact of these policies is understood, recommendations can be developed concerning the improvement of programs and policies designed to achieve legislative and judicial goals. After answering the research questions listed earlier, we present specific policy and program recommendations based on our analyses. We hope that the information provided here and the ensuing recommendations lead to concrete steps that will improve the lives of mentally retarded children and their families.

A Statement of Personal Values

We believe it is the responsibility of researchers working in this conflicted and complex field to disclose the personal values that may affect the conduct of their work and analysis of their findings. Because value-free research in the social sciences is an unattainable (and perhaps undesirable) goal, it is incumbent on investigators to make clear the ideological and evaluative positions that either directly or indirectly color their perceptions, questions, methodologies, analyses, and recommendations. When the consumer of research information is made aware of these underlying biases, he or she may then better judge the validity or truth of what is offered as fact. To this end, we offer the following value statements and ideological tenets. The critical reader of the data and analyses that are presented in this report should bear in mind these statements.

1) The social policies affecting handicapped children that have evolved over the past 20 years from statutory law and common law are appropriate and worthy of continuation.
2) The philosophical principle of normalization and its various practical embodiments (e.g., mainstreaming, use of least restrictive alternatives, communitization, self-determination, etc.) should be implemented across all social institutions and structures.

3) The most effective and appropriate environment for the development of handicapped children is that of the natural family. Any decision to move a child out of this environment represents a potential infringement upon the sanctity of the family structure and interference with the child's basic human rights. Therefore, care that occurs outside of the family context must be clearly beneficial to the child's full development.

4) Children learn best in schools close to their homes where they have infinite opportunities to play and work with their friends and peers. Any removal from the normal school environment represents a threat to a child's right to achieve his or her full potential, and therefore must be clearly justified with regard to his or her extraordinary needs.

5) Society as a whole has an inherent obligation to assure that the financial, material, and human resources necessary for the support and treatment of handicapped children and their families are made available and accessible.

Chapter Two

Statement of the Problem

Historical Overview

This report is about a contemporary problem with roots that extend back some 200 years. Ever since 1799, when Jean-Marc Gaspard Itard began his attempts to teach Victor, the Wild Boy of Aveyron, acceptable behavior and rudimentary academic skills, the field of special education has been devoted to improving the development of children with handicapping conditions. With varying degrees of philosophical commitment and success, special educators have sought to assist handicapped children to become independent and accepted members of the communities in which they live. The current trend to integrate severely handicapped children into local schools and other social environments, which is the focus of this report, is due in part to earlier trends which emphasized the segregation of those children.

Hope, Reform, and Despair in the Nineteenth Century

In the United States, special education began in the 1820s, when special residential schools were first established. The purpose of these early schools was laudable if unrealistic. Pioneers such as Samuel Gridley Howe and Edouard Sequin hoped that short-term residential care and treatment, based on simple behavior modification and sensory training techniques, would lead to complete cure and the development of a normal child. Low staff ratios, trained professionals, stimulating environments, supportive facilities located as close to a child's home as possible, and attention to the spiritual and moral domains were to lead to radical and permanent changes in children identified as idiots,

epileptics, or lunatics. As a Massachusetts legislative committee, chaired by Samuel Howe, wrote in 1848:

> The benefits to be derived from the establishment of a school for this class of persons, upon humane and scientific principles would be very great. Not only would all the idiots who should be received into it be improved in their bodily and mental condition, but all the others in the State and the country would be indirectly benefitted. The school, if conducted by persons of skill and ability, would be a model for others. Valuable information would be disseminated throughout the country; it would be demonstrated that no idiot need be confined or restrained by force; that the young can be trained for industry, order, and self-respect; that they can be redeemed from odious and filthy habits; and there is not one of any age who may not be made more of a man and less of a brute by patience and kindness directed by energy and skill. (Howe, 1848)

Howe and his contemporaries were particularly optimistic about the potential for remediating children. Predating the establishment of compulsory public education for normal children, Howe and others founded schools for blind, retarded, and epileptic children in the northeastern United States, many of which continue into the present.

As the schools developed some experience through the middle part of the 19th century, the emphasis began to shift from short-term to long-term care. It became apparent that severe disabilities were not curable, at least in the short-term, and that an important goal of care was protection in addition to treatment. With the increasing industrialization of urban America, increased ethnic heterogeneity, and inadequate or absent social services, humanitarians such as Dorothea Dix argued that people with mental illness or retardation should be congregated into "asylums in which they may be surrounded with every needed care" (Dix, 1846). Thus the rationale for treating retarded children shifted at mid-century to a model of protection rather than habilitation.

Concurrent with this shift, the advent of industrialization brought into existence new models of organizational management. It became obvious that large-scale production in centralized facilities was more cost-effective and manageable than small-scale, dispersed operations. This notion was applied to the emerging practice of social service, including institutional care for disabled people. The result was a belief that large institutions, particularly those that could produce their own goods and services, were most desirable. This led to the common practice of establishing "farm colonies." The colonies were doubly beneficial. While saving the taxpayer money through economies of scale, they would provide a secure, isolated setting where practical skills could be taught. A less laudable purpose, but an important impetus in the farm colony movement, was reflected in a report issued in 1892:

> Children feeble in mind, mentally deficient or diseased, or both, abound in the homes of the poor, swarm the slums, wander the streets and obtrude upon the legitimate work of the public schools. (in Osborne, 1894, p. 1084)

The rationale for colonization was, therefore, not only protection of the child from society, but protection of society and its institutions from the child. The higher goals of treatment and economic self-sufficiency which provided the initial impetus for rural institutions soon were subverted into more narrow goals of isolation and economization.

The practice of isolating children and adults with mental retardation was given further support by several historical developments. By the late 19th century, masses of European immigrants were coming to the major urban centers of the United States. Given the prevailing

ethnocentric views of civilization held by the English-speaking societies, immigrants were viewed as less civilized, less intelligent, less skilled people who were a threat both to the economic and moral development of America. Failure to speak English and conform with the prevailing social norms of late Victorian society led to a perception that immigrants were deviants and contributors to the phenomena of retardation and insanity. Perpetuating this view were the undeniable circumstances of extreme poverty and destitution many immigrants experienced. The concomitants of urban poverty -- alcoholism, crime, prostitution -- were seen as both cause and effect of retardation, and a struggling, increasingly materialistic and competitive society had no trouble singling out the perceived cause of these ills -- "the half a million tramps, cranks, and peripatetic beggars crawling like human parasites over our body politic, and feasting upon the rich juices of productive labor," who had been "burdened with the accumulated inherent sins of a vitiated and depraved ancestry,...bred in filth,...born in squalor, and raised in an atmosphere tainted of course with crime.... Handicapped by the vices of their inheritance they are simply not strong enough to keep up to the social, civil, and moral ethics of the age, and as an inevitable consequence, just as water seeks its level, they drop back by degrees to become in turn deficient, delinquent, defective, and dependent" (Osborne, 1894, p. 393).

Fuel for this ethnocentric fire was provided handily by the new understanding of human evolution that Charles Darwin, Francis Galton, and Herbert Spencer offered. By applying the precepts of biological evolution to human societies, an argument was made that mental retardation was due almost exclusively to a degenerate gene pool, which

happened to be found in high concentration among immigrants and other members of the urban poor. Awareness of the existence and effects of genes led to the hope that retardation was controllable through biosocial engineering. If deficient, deviant people could be isolated from society, and kept from procreating among themselves, the American "race" could evolve unfettered to the great capacities for which it was destined. Urban ills would be ameliorated and retardation could be genetically eliminated. People who were retarded would be provided custodial care and no more, because their genetic endowment prohibited them from gaining any benefit from the kind of treatment-oriented institutions characteristic of earlier times. In many ways, the creation of genetic science led to a major setback in the evolution of services for people who were retarded.

A parallel and related development was emerging in France at the end of the century. Alfred Binet, with his student Theodore Simon, investigated the relationship among children's behavior, their mental capacities, and school performance. They observed that some children, who displayed "less intelligence," could be predicted to not succeed at academic tasks (Scheerenberger, 1983). In 1907, when France decided to provide special classes for children with subnormal intelligence, the government turned to Binet to develop a means for measuring intelligence. This early scale, intended to distinguish between normal and subnormal school-age children, also sought to identify the educational consequences of different levels of retardation. In 1916, Lewis Terman from Stanford University translated the Binet Scale into the Stanford-Binet Test of Intelligence, and the means for classifying and separating mentally retarded children were now available to public school personnel.

A Half-Century of Fear and Isolation

These interrelated social and scientific developments had a lasting impact on the way children with mental retardation were treated (or not treated) during the 20th century. By the beginning of the first World War, institutional care consisted of custodial warehousing. Residents were required to perform work not for habilitative reasons but to reduce the costs of operations. Educational and vocational programs were non-existent. There was no intention of returning retarded people to their home communities. Institutions were intended to keep retarded people away from society and from reproducing. Mandatory sterilization of institutional residents and retarded people living outside of institutions became prevalent, and was sanctioned by the U. S. Supreme Court in 1927. Given a genetically-based view of intelligence, special education programs were offered rarely, and always in buildings separated from those of normal children. Testing was used to classify and segregate, not as a basis for educational programming. Special classes were to benefit normal children by removing "defective learners" from the setting. Little was expected in terms of educational benefit for the handicapped child who was so removed, and a self-fulfilling prophecy was created as less and less money was appropriated to support special classes. This lack of clear rationale for special classes was paralleled in institutional settings, which enjoyed little public concern or commitment by this point.

There were some signs of progressive reform during the 1920s and 1930s. In particular, advocates for community-based care and meaningful education were defining new approaches, or resurrecting abandoned ones. In Massachusetts, Walter E. Fernald, after first

adopting the pessimistic views of his scientific peers, began to push for legislation that would establish: 1) a census of retarded children and adults, 2) school-based diagnostic clinics, 3) home and community-based care, and 4) separate facilities for delinquent and retarded youth. In New York, Charles Bernstein led a movement to provide alternative community residences for children. He also advocated for the use of individualized programs of treatment, a previously unheard of approach (perhaps because it did not fit well with the corporate-industrial ideology of mass production then so prevalent in schools as well as business). By 1935, Bernstein had created a network of 52 group homes in New York. Early studies of those relatively few people who were released from institutions indicated some hope. In a follow-up of discharged residents in Massachusetts, it was found that 60 percent of the men and 36 percent of the women were succeeding in their local communities (Fernald, 1919). In sum, the general trends from the turn of the century to the Great Depression were negative in terms of advances in education and care, but experimental programs were being developed to demonstrate alternative approaches, and evidence was emerging that those alternative approaches held some promise (Scheerenberger, 1983).

In the schools, new policies were having measurable impact. New Jersey was the first state to enact mandatory special education for mentally retarded children, in 1911. Most other states soon followed suit. However, the purpose of these classes, as indicated earlier, was segregation, not education leading to independence. Most special education programs were limited to severely handicapped children whose

IQ score fell below 50. Mildly and moderately retarded children either stayed at home or struggled in regular schools. In one follow-up study of special school graduates, Farrell (1915) found evidence that good programs can produce concrete benefits. Ninety-two percent of her study group (n=350) had attended school until age 16 (far above the prevailing rate among normal children), 54.8 percent were gainfully employed, 24.6 percent were being cared for at home, and only five percent were in an institution or prison.

The 1930s and 1940s did not produce significant new developments in the care and treatment of people with mental retardation. Preoccupied first with economic catastrophy and next with the Second World War, American energies were devoted to creating jobs and preserving liberty, not the protection or education of people who were viewed as incapable of contributing to either jobs or liberty. In a time of economic crisis and fear of foreign invasion, earlier regressive approaches were revived. Immigration laws were strengthened, with particular emphasis on excluding retarded people. Mandatory sterilization laws were enforced aggressively. Institutions were filled beyond capacity, and rates of new admissions increased, especially during the Depression. Overcrowding and impersonal treatment were common, and educational programming was negligible. Rates of return to community living were low, with less than one-quarter of institutionalized people being "paroled" in the late 1930s (Frankel, 1938). Homes for dependent children, county poor farms, and alms houses, the best of which provided barely acceptable living conditions, were also used frequently in this era.

Post-War Reform

The Second World War led to a revitalization of attempts to appropriately care for and educate people with retardation. The War offered many opportunities to develop new forms of rehabilitative treatment for physically injured or mentally ill soldiers. Post-war prosperity created more positive social conditions and attitudes, and the horrible lessons of the Third Reich, which exterminated at least 100,000 mentally handicapped children and adults (Scheererberger, 1983) were not ignored in the United States.

In 1950, parents of mentally retarded children formed the National Association for Retarded Children. Throughout the 1950s, the NARC advocated successfully for special schools for moderately and severely retarded children. Research and teacher training programs were developed at several universities. Leaders in the field of special education, notably Samuel Kirk and Lloyd Dunn, began to develop systematic curricula for retarded children based on their level of disability. Primary emphasis was placed on the use of special or self-contained classes in public schools, although a minority argued for placement in regular classrooms. These minority viewpoints are summarized by Tenny (1953), who argued that the,

> segregated nature of our special education programs have prevented the non-handicapped majority from intimate contact with the handicapped in school and probably also discourages out of school contacts. Understanding and acceptance come about most readily through individual acquaintance; therefore segregation should be eliminated whenever possible. (p. 264)

This enlightened view was at least two decades ahead of its time. The 1950s and 1960s continued to be characterized by segregated educational and residential services for retarded children.

Institutions remained a major locus of care for retarded children, but they were stagnant, overcrowded, custodial places, and both professionals and parents were gaining a growing appreciation of these realities. One reformer (Roselle, 1954, p. 597) suggested that institutionalized children have "certain special and inalienable rights...to live in homes and communities which approach as nearly as possible the desirable standards of normal homes and communities." Others called for uniform standards in residential institutions, the use of due process procedures during institutional admission, and greater reliance on community alternatives such as foster care.

The Era of Civil Rights

These reformist notions remained just that until a series of political, economic, and social developments coincided in the early 1960s to lead to real change in treatment practices. With the election of John F. Kennedy to the Presidency in 1960, national policy began to accelerate the development of community-based care. Kennedy, for both personal and philosophical reasons, founded the President's Commission on Mental Retardation in 1962, indicating a desire for the federal government to take an active leadership role. The Commission's work led directly to the passage of P.L. 88-164, the Community Mental Health and Mental Retardation Facilities Construction Act of 1963. This landmark legislation provided, for the first time, federal dollars for community-based treatment. The Act's language reflected a new understanding of human intelligence, which was now viewed as plastic and responsive to environmental conditions, not genetically fixed and predetermined. Researchers such as Kirk (1958), Hunt (1961), and Bloom

(1964) demonstrated that education, beginning in the early childhood years, could reduce both the likelihood that children would become retarded and the degree of retardation in children already exhibiting developmental problems.

New understandings of children's development paralleled new approaches to community-based care. Hobbs (1964) identified a "third revolution in mental health" occurring in the mid-20th century. The first revolution was characterized by Howe's belief that mental impairments were remediable. The second revolution occurred when reformers like Dix advocated for humane and appropriate institutional care. The third revolution, one which continues today, was marked by a commitment to treat disabled people in their own communities with non-disabled people whenever possible. The availability of psychotropic drugs, more successful behavior management techniques, and a philosophical belief in use of the least restrictive placement alternative combined to give impetus to this most recent revolution.

Social circumstances in the 1960s also perpetuated increased reliance on community care. Economic prosperity supported the expansion of research, teacher training, and special education programs. President Johnson's War on Poverty contained many educational and vocational components which benefitted disadvantaged and minority people who were at risk for being identified as mentally retarded. Head Start, Follow Through, the Elementary and Secondary Education Act (including Title I), and the Job Corps were model attempts to improve the environments in which people lived and worked in order to prevent or ameliorate mental retardation. In addition,

civil rights legislation and litigation were enlarging the notion of a constitutional guarantee to equal opportunity. Rights to education, jobs, housing, and political power were more clearly defined and protected, benefitting not only racial or ethnic minorities, but handicapped people as well. The 1954 Supreme Court decision in Brown v. Board of Education was interpreted to apply to any group treated in a "separate but equal" manner.

These social and political trends accelerated remarkably in the 1970s. A series of federal court decisions from 1970 to 1974 established the following principles:

1. Mentally retarded children may not be excluded from public school simply because they are difficult to educate or because the schools are inadequately prepared to meet their needs (PARC v. Commonwealth of Pennsylvania, 1972).

2. Lack of funds is not an acceptable justification for excluding handicapped children (Mills v. District of Columbia, 1972).

3. IQ scores alone are not a sufficient or valid basis for labeling children as mentally retarded, particularly minority children (Larry P. v. Riles, 1972).

4. Institutionalized residents have a right to be free from harm and have a right to be treated in the most normal, least restrictive environment possible (Wyatt v. Stickney, 1970; New York ARC v. Rockefeller, 1972).

5. The most severely, profoundly handicapped children have a right to a free appropriate public education (Mills v. District of Columbia, 1972; Maryland ARC v. State of Maryland, 1974).

Policies Affecting Educational Services

As these cases were litigated and resolved, state and federal governments enacted complementary laws to assure the education of handicapped children. In the 1971-72 legislative season, states enacted almost 300 bills relative to special education services. By 1975, only two states had permissive legislation; all others had enacted mandatory requirements for the education of handicapped children. The federal government followed suit with the passage of P.L. 94-142, the Education for All Handicapped Children Act of 1975. Cited as one of the most significant and specific pieces of social legislation ever enacted, the law had five basic tenets:

1. All handicapped children between 3 and 21 have a right to a free appropriate public education.

2. Handicapped children have a right to nondiscriminatory testing, evaluation, and placement procedures.

3. Handicapped children have a right to be educated in the least restrictive environment.

4. Handicapped children's parents have a right to full participation in all decisions affecting the education of their children.

5. Handicapped children and their parents have a right to the procedural due process of law.

These rights, which went into full effect in the 1978-79 school year, established minimum guarantees which were to be provided in all states. In reality, all states already had laws that equalled or surpassed these requirements.

Another major federal law that has affected handicapped children, particularly those who have resided in institutions, is P.L. 89-313, the Federal Assistance to State Operated and Supported Schools for the Handicapped Act of 1965. Under this amendment to the Elementary and Secondary Education Act, funds are provided to states for education and related services to handicapped children in public residential institutions or state operated schools. Grants are also made to local education agencies to support handicapped children who were formerly enrolled in state institutions or schools. This support is intended to act as an incentive for states to provide appropriate educational programs in institutions as well as in local communities. Requirements for services and funding are identical to those found in P.L. 94-142.

In 1973, Congress passed the Rehabilitation Act, which included Section 504. This section, which was based on the 14th Amendment of the U. S. Constitution and was a logical extension of the 1964 Civil Rights Act, forbids discrimination against handicapped people in any program or activity receiving federal financial assistance. Specifically, people with physical or mental impairments must have equal access and opportunities in educational and vocational training programs. Equal access is to be assured through use of barrier-free facilities, non-discriminatory testing and instructional methods, and placement in the least restrictive alternative. Unlike P.L. 94-142, which establishes a set of rules for delivery of federally-funded special education services, Section 504 is essentially a guarantee of civil rights. It does not create or subsidize treatment programs. It simply protects handicapped individuals (as well as people with drug addiction and alcoholism) who participate in such programs. Also

unlike P.L. 94-142, Section 504 allows individuals to bring private suits against institutions or agencies that discriminate, and monetary damages may be awarded when discrimination has been found to occur.

Neither P.L. 94-142 nor Section 504 took effect at the time they were signed into law. Because of their broad scope, the complexity of rule promulgation, and some foot-dragging by the Cabinet Secretaries responsible for the two laws, regulations for P.L. 94-142 were not issued until August, 1977, with an effective date of September, 1978. Regulations for Section 504 were not signed into law until 1977, four years after the Section's legislative approval.

In 1983, Congress reauthorized the non-permanent sections of P.L. 94-142, adding several important amendments that affect specific groups of handicapped children.* The amended act, P.L. 98-199, increases the monitoring and evaluation requirements for federal and state agencies; allows use of federal funds for handicapped children beginning at birth; and establishes a new program initiative to (a) facilitate the transition of handicapped youth from secondary school to work or higher education, and (b) support model secondary special education programs. The significant aspects of the 1983 amendments, and most regulatory and program development activity now occurring, focus primarily on the early childhood and young adult years. It is clear that the current priorities of the U. S. Office of Special Education reflect the importance of early intervention to reduce the long-term consequences

*The basic state grant program, Part B, has permanent authorization. That is, the basic requirements that handicapped children receive a free appropriate public education, and that states will receive federal subsidies to provide this education, will not expire unless the law itself is repealed.

of handicapping conditions and school-to-work transition services to assure successful employment and self-sufficiency.

It should be noted that federal appropriations have never matched authorization levels. Although Part B of P.L. 94-142 allows for subsidies equal to 40 percent of the national average costs of educating a non-handicapped child, appropriations have actually provided only about 11 percent of that figure, or $193 per handicapped child per year in 1984-85.

Policies Affecting Community Services

Federal and state governments have also been active in non-educational policy making. As was the case with P.L. 94-142, broad-aim social policies have been enacted that have ambitious goals, very specific requirements, and insufficient money to fully realize those goals and requirements. At the federal level, the most significant of these laws is the Developmental Disabilities Assistance and Bill of Rights Act of 1975, which was a descendant ot the Mental Retardation Facilities Construction Act of 1963, described earlier. The 1975 version, like its predecessors, provided funds to states for the establishment of comprehensive services to people with developmental disabilities. Developmentally disabled people are those with impairments related to mental retardation, cerebral palsy, epilepsy, autism, dyslexia, or other neurological conditions similar to retardation which are manifested during childhood. State planning councils, advocacy systems, institutional reform, deinstitutionalization, and creation of community-based services were all required under the

1975 amendments. In 1978, the Act was amended by P.L. 95-602, the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments. These amendments are significant in that they move toward a noncategorical system for defining the eligible beneficiaries of services. Specific handicapping conditions such as mental retardation or autism are no longer mentioned. Rather, an individual must have severe limitations in a functional ability such as speaking, walking, or self-care in order to receive care and treatment subsidized by this Act.

The provisions of this Act have been interpreted in various ways. Some advocates have argued that its intent is to mandate community-based residential and social services, and institutional services should not be subsidized through it. Others claim that it mandates nothing. The law is simply a funding mechanism for assisting states in the provision of both institutional and community care. The latter point of view has been essentially affirmed by the U. S. Supreme Court in Halderman v. Pennhurst (1981). In this case, the Court ruled that P.L. 95-602 "does not create any substantive rights to appropriate treatment in the least restrictive environment" (Bradley, 1985, p. 84). Although a lower court had, in 1977, found institutional care to be inherently inappropriate and restrictive, the subsequent Supreme Court ruling was more conservative. The 1981 decision implied that federal courts would only be interested in protecting the rights of institutionalized people, not in creating new social policies that mandated community-based care. The Pennhurst decision served as guiding precedent in the Garrity V. Gallen (1981) litigation which

occurred in New Hampshire, in which Judge Devine ordered both institutional reform and expansion of community services, but declined the plaintiffs' request for closure of the institution. In sum, it appears that federal special education law does provide a mandate and guarantee for appropriate services, while laws supporting other kinds of services (residential, vocational, social) are permissive and non-binding with respect to states' participation.

Recently, there has been a federal attempt to make community based care mandatory through Senate Bill S. 2053, the Community and Family Living Amendments of 1983. The bill called for the gradual phase-out and eventual closure of large state institutions (through exclusive use of federal Medicaid dollars in small community facilities). Increased appropriations for Medicaid funds would help to expand community services, and a broader array of services, such as personal aides, domestic help, family support, respite care, staff training, and case management would be reimburseable under Medicaid. The bill drew a good deal of fire from advocates for institutional care, including parent organizations such as the National Association for Retarded Citizens. NARC, in voting to oppose the bill, argued for a full range of residential and treatment alternatives, <u>including</u> institutional care when necessary. Part of the parental opposition was aimed at a provision in S. 2053 that would have allowed the deinstitutionalization of individuals in spite of parent objection. The bill did not come to a floor vote, but a modified, less radical version was reintroduced in the 1985 session of Congress.

New Hampshire History

New Hampshire's experiences with services to handicapped children closely parallel the national experience just described. The New Hampshire School for the Feebleminded was established in 1903 in a rural area about 35 miles north of the state capitol. The School was a typical farm colony, located on a prime agricultural tract near Lake Winnipesaukee. The original legislative intent in creating the School was to provide special services for children only, but "adult defectives" were soon admitted as well. The School was to act as a,

> safeguard whereby society may protect itself from the vice, corruption, and licentiousness with which it is threatened when anyone of this defective class is left unrestrained and unprotected in the community. (Second Biennial Report of the Trustees of the New Hampshire School for the Feebleminded, September 30, 1904, p. 21; cited in Garrity v. Gallen, 1981, p. 13)

The School grew steadily from its original 60 residents in 1903 to a peak of 1,167 residents in 1970. At the time of the litigation in 1979, 564 residents lived at the School. Eighty of these (14.2%) were under 21 years old. Of the total population, 57 percent had been institutionalized more than 20 years; 32 percent had been there for 10 to 20 years. During its eighty-two year history, the School practiced the commonly accepted treatments of each era, from mandatory sterilization to physical restraints to heavy reliance on tranquilizers and barbituates to behavioral conditioning techniques. Testimony entered by the plaintiffs in the Garrity v. Gallen trial provided vivid illustrations of long-term resident abuse, developmental regression, unsanitary conditions, inadequate and untrained staff, little effort to

place people in communities, unaccredited and unsafe facilities, few treatment programs, and little attention or support from the state legislature. Expert witnesses described the School as either representative of similar institutions in other states or somewhat worse in comparison.

Community services for mentally retarded children in New Hampshire have also been less than exemplary. Until quite recently, there have been very few residential alternatives other than the State School for families experiencing difficulty in caring for their retarded children at home. This has created a one-option system in which children with extreme behavioral or medical problems either stayed home, causing severe family stress, or went to the State School (or State Hospital, which was occasionally used as a "holding tank" for children waiting to be admitted to the School). Once at the School, children could only leave if their parents or relatives took them into their own homes or made private arrangements in boarding homes, nursing homes, or other inappropriate facilities. Although institutionalized children have been found to be easier to place and care for than adults, the lack of community placements created pressure on LSS up until the 1970s to keep children there.

In the early 1970s, the State Office of Mental Retardation set as a goal the creation of community based developmental centers for children, and worked toward prohibiting further admissions of children to LSS. By the mid-1970s, OMR was actively pulling children out and placing them in local public school programs. However, as was the case elsewhere, the most severely handicapped children and those without family or advocates tended to remain.

Special education services in New Hampshire have also reflected national trends. In 1965, NH RSA 186:A was enacted with the broad aim of providing "the best and most effective education possible to all handicapped children in New Hampshire" (RSA 186:A:1). The law appeared to be progressive and well-intended, but its specific language created a good deal of leeway in interpretation and implementation. The law was actually more permissive than mandatory. It allowed school districts to establish classes for intellectually or emotionally handicapped children, but did not require that these children be educated. It did require the education of physically handicapped children, even up to age 31 in some cases. Local districts were liable for a handicapped child's tuition. Excess costs above average tuition levels were not subsidized by the state.

By 1974, this permissive language was leading to significant problems. In a budgetary crisis that year, the state legislature decided to transfer $500,000 from the special education budget to the Aid to Families with Dependent Children (AFDC) budget. This seriously impaired the ability of the state to provide "the best and most effective education possible." At the same time, the legislature shifted the special education funding mechanism from per-child allocations to program-based allocations. This had the immediate effect of stimulating program development on a regional basis. By 1976, 18 special education regional consortia had formed to provide contracted services to local member districts. Under this system, handicapped children often attended regional programs away from their home districts, thus perpetuating segregated treatment.

The passage of P.L. 94-142 in 1975 and its full implementation in 1978 created pressures to clarify the special education mandate and move away from a regionalized system. Requirements for least restrictive placements and federal allocations based on child counts rather than program efforts resulted in major amendments to state law. Essentially the law was amended to require special education for all handicapped children between 3 and 21 years old. No longer could children be excluded because they were deemed not "capable of being benefitted by instruction" (1965 language).

In 1981, the state legislature repealed RSA 186:A and replaced it with RSA 186:C. The new law established a funding formula which was intended to equalize special education allocations across property-wealthy and property-poor school districts. This was the first attempt at equalizing education funding in New Hampshire. The legislature subsequently adopted an equalization formula applicable to all areas of state-funded education in 1985.

The 1981 law also ended state subsidization of per pupil costs that exceeded twice the state average tuition costs for nonhandicapped children. A new approach referred to as "castastrophic aid" was implemented. Catastrophic aid was to be made available to a local district whenever a handicapped child's educational costs exceeded $9,000. At that point, the state would provide 80 percent of the additional costs. However, based on the actual number of catastrophic cases, the state would need to appropriate about $4.2 million, based on FY '84 figures. The actual appropriation for catastrophic aid has been about $1.25 million since 1981. Local school districts have therefore

had to make up the $2.9 million difference. In FY '84, 757 students were eligible for catastrophic aid. This represents 4.3 percent of the 17,579 educationally handicapped children identified in New Hampshire as of April, 1984. The actual cost to local school districts for these 757 children was about $9.7 million; the state provided an additional $1.25 million. Average annual tuition costs for these severely handicapped children was just under $16,000. Many of these severely handicapped children are at risk for institutionalization if adequate community-based services are not available.

It should be noted that federal appropriations have done little to ease local costs. As indicated earlier, Part B of P.L. 94-142 provided about $193 per handicapped child during FY '85. That is the equivalent of just over two days of service for a child whose educational costs are $16,000 and who attends school 180 days per year. Additional funds are made available to previously institutionalized children and those at risk for institutionalization under P.L. 89-313. This subsidy amounted to $525 per child in FY '85, or about 6 days of service for the severely handicapped child. Clearly these federal appropriations do very little to offset the financial burden on local school districts responsible under federal and state laws to provide a free appropriate public education to all handicapped children.

In 1985, the legislature took major steps to equalize state education spending. Under threat of a law suit from property-poor towns, the legislature enacted what is known as the Augenblick formula. The $8.1 million previously earmarked for special education under RSA 186:C was made a part of a total aid package which included foundation

aid, Sweepstakes aid, and basic special education aid. The formula allocates funds according to an individual district's (a) type of special education services and the numbers of students at various grade levels, (b) property wealth, (c) per capita income, and (d) property tax rate. The law also sets as a goal a total appropriation level equal to 8 percent of the educational expenses in an average district. However, that goal is a distant one given that $50 million is needed to reach it and $24.3 million was actually appropriated for FY '86. Finally, the 1985 legislature also increased the catastrophic aid appropriation by 35 percent for FY '86, to $1.64 million..

This history of special education services in New Hampshire demonstrates a clear philosophical commitment to providing appropriate programs that is not supported by state-level funding. Since 1965, the state has provided varying levels of financial support in order to assist local school districts deliver special education services. That support has increased incrementally in the past five years. The primary burden for covering special education costs remains with local districts. Reliance on the local property tax to pay for about 85 percent of the costs of educating children has resulted in resistance to expanded funding for handicapped children, particularly when those children are severely handicapped and require intensive and expensive treatment.

In the past, local school districts could send severely handicapped and mentally retarded children to the Laconia State School. Because the residential and educational expenses incurred at LSS were paid for out of the state operating budget rather than local school

budgets, such a placement was obviously the easiest way to deal with the education of a child who required extraordinary support. "Out of sight -- out of mind" seemed to be the prevailing practice. However, by the mid to late 1970s, state and federal policies and the early stages of the Garrity v. Gallen litigation acted to counter this simple approach. Statutory requirements for (a) individualized education, (b) placement in least restrictive alternatives, (c) opportunities to interact with nonhandicapped peers, and (d) decision-making by multidisciplinary teams representing a child's local school district meant that placement at LSS could only occur as a last resort and with full involvement by the child's local school district and his or her parents. The order issued by Judge Devine in Garrity v. Gallen summarizes concisely what the pre-1981 practices were and why they were deficient.

> Whether out of timidity in the face of [the] powerful local voice, out of deference to the local taxpayers who are primarily footing the bill for education in the state, or out of sheer abdication of responsibility, the State Board of Education has failed to fulfill its responsibility of enforcing the EHCA [Education of Handicapped Children Act] and RSA 186-C. Far from being the driving force behind the towns and cities, the State too often ends up "passing the buck", and indeed, in the past has failed to live up to its own statutory responsibilities by failing to reimburse the towns and cities for the excess cost of education, as required by RSA 186-A (now repealed). All too often in the past LSS has served as a repository for children whose own school district cannot or will not provide for them. Children often end up at LSS not because it has been deemed, after careful consideration, to be the most suitable placement for them among an array of alternative services, but for reasons completely unrelated to their best educational interests. Parents, often extremely well meaning, have become utterly frustrated with caring for their mentally retarded children at home. Local school districts,

already under fire from angry property taxpayers for the cost of education, refuse to accommodate the special needs of these children in their own schools or to fund alternative local placements; instead, they deposit the child in the lap of the State and consider their task to be done. (p. 134)

The evidence at trial revealed that the local education agencies (LEAs) fail to take responsibility for children at LSS who originated in their districts, and that the State has failed to exert pressure on them to do so. In effect, LSS has assumed the role of the LEAs. The School and its administration had, at the time of trial, developed Individual Education Plans (IEPs) for the approximately ninety children residing there. But Edward DeForrest, Director of Special Education for the State, testified that less than twenty-five percent of the school districts from which these children have come are involved in the formulation and review of these IEPs. (pp. 136-137)

Without participation from the LEAs, children at LSS lose an effective advocate, and in some instances, they lose their only outside advocate. As mentioned above, at the inception of this trial, several children between the ages of three and twenty-one were without parents or guardians. At the time of trial ten children were without parents, fifteen percent had limited contact from their parents, thirty-five to fifty percent had little if any contact. Only twenty-eight percent of the parents are involved in the IEP process. (pp. 138-139)

In conclusion, the crossed lines of authority and lack of accountability for educationally handicapped children in New Hampshire has created the perverse situation that the children in greatest need of services and individual attention often receive the least care and attention. Local school districts serve non-handicapped students, but see LSS as an oasis in which they can discard their more difficult and more costly handicapped students. Even assuming that the State exercises good faith in attempting to pick up the slack and to provide an adequate education to students at LSS, the fact is that for many children, LSS is a wasteland. Without prodding from interested parties such as parents, guardians, or surrogate parents and the LEA, as envisioned by the EHCA, the State becomes, in effect, the guardian of the child and the reviewer of its own programs. Not surprisingly, as its own appeals court, the State has been extremely lenient on itself. There being a small pie to begin with, education at LSS gets a very small slice. (pp. 140-141)

For the present, it seems that Laconia State School is not an appropriate alternative placement for severely handicapped children. Only 3 children have been admitted to LSS since the beginning of 1982. Since the early 1970s, as will be seen in the next section, the direction of movement has been from LSS back to local communities. It is the consequences of this movement that are of primary concern in this study.

The Deinstitutionalization Movement

Institutional Growth and Decline

The size of public institutions for people with mental retardation grew steadily from their inception in the 19th century to the late 1960s. In 1904, for example, there were 14,743 people in mental retardation institutions in the United States. In 1930, the number had grown to 72,565. By 1946, there were 119,456 institutionalized people (Kirk & Spalding, 1953). In 1960, there were slightly over 160,000 mentally retarded people in public institutions. In 1968, the number peaked at about 190,000 people (Conroy & Bradley, 1985). The average size of a public institution in 1967 was 1,250 residents (Bruininks, Meyers, Sigford, & Lakin, 1981).

Since the late 1960s, there has been a steady decline in the number of residents in large public institutions, a decline in the average size of public institutions, and a significant proliferation in the number of smaller, community-based facilities. In 1983, there were

slightly over 100,000 people in public institutions (Conroy & Bradley, 1985). In 1975, the average size of large public institutions was 700 (Conroy, 1977), down by 44 percent over an eight-year period. By 1982, large institutions (those with an average size of 366 residents) were reducing their enrollments by 5.6 percent annually, while all other forms of residential care were growing. Sixty percent of all group homes that existed in 1982 had opened in the past four and one-half years. In the five year period preceding 1982, the number of group homes with less than 15 people increased by 98.9 percent nationally, and the number of people living in such homes grew by 87.2 percent (Hill & Lakin, 1984).

The population that has most often made up the group that has left large institutions to live in smaller community-based facilities has been younger and less retarded compared to those who have remained. Children (those individuals under 21 years old) went from having the highest rate of institutionalization in the late 1960s to the lowest rate by the late 1970s. Children left institutions at a higher rate than adults throughout the 1970s. Thirty-two percent of all discharges from institutions in the mid-1970s were children from 6 to 18 years old (Wyngaarden & Gollay, 1976). By 1982, less than 25 percent of institutional residents were under 22 years old (Hauber, Bruininks, Hill, Lakin, & White, 1982). As Hill and Lakin (1984, p. 13) have noted:

> The decrease in the number of children and youth in the residential care system is a dramatic and socially significant finding. This result of social policies creating and funding community-based education and support programs for children and their families is one in which advocates may feel some justifiable pride.

As children have left institutions over the past fifteen years, trends in the degree of their handicapping conditions are notable. Beginning in the late 1960s, institutional admission criteria became more stringent, resulting in fewer admissions of mildly retarded children and non-retarded children with physical handicaps. By 1979, 61 percent of new admissions were for people with severe or profound mental retardation, a substantially higher proportion than occurred in previous years (Scheerenberger, 1981; Willer & Intagliata, 1984). In the five-year period prior to 1982, profoundly retarded residents increased in proportion to all other categories of retardation of institutional residents. During the same period, the proportion of profoundly retarded residents in group homes more than doubled, and severely retarded residents in group homes also increased compared to mildly and moderately retarded people (Hill & Lakin, 1984).

Deinstitutionalization of Children

Very few studies of the deinstitutionalization of children have been published. Most community placement/adjustment research has focused exclusively on adults or has combined adults and children in the reporting of findings. For example, in a review by Freedman (1976) of 28 studies, only two of these included subjects less than 21 years old, and those two studies emphasized adult measures of success such as independent living, marital relations, and employment rather than child-appropriate criteria such as educational placement and family adjustment. More recent investigations or reviews (Eyman & Arndt, 1982; Landesman-Dwyer, 1982; Schalock, Harper, & Carver, 1981; Willer & Intagliata, 1981, 1982) have continued to ignore the status of

deinstitutionalized children, especially with regard to the provision of educational services. In a comprehensive review of 30 deinstitutionalization studies that were published between 1980 and 1985, Mallory and Herrick (in press) found only 4 studies in which the average age of subjects was below 21. (cf. Ellis, Bostick, Moore, & Taylor, 1981; Heller, 1982; Reagan, Murphy, Hill, & Thomas, 1980; Seltzer & Krauss, 1984). The most comprehensive study, that of Seltzer and Krauss (1984), will be discussed below.

Studies that include both children and adults have often compared the outcomes of deinstitutionalization for the two age groups. Gollay (1976) and Freedman, Wyngaarden, and Gollay (1976) found that: (a) children who leave institutions are more likely to be severely and profoundly retarded than released adults; (b) children are almost twice as likely to be placed in natural or adoptive homes as adults; (c) adults are twice as likely to be placed in group homes as children; (d) children are less likely to return to institutions than adults; (e) children are perceived as having fewer unmet needs and causing fewer problems than adults; and (f) communities may be more accepting and supportive of deinstitutionalized children compared to adults. Additional comparative work has been done by Nihira and Nihira (1975), who found that children placed in community settings were more likely to exhibit jeopardizing behaviors (endangering the health and safety of self and others) than adults.

Studies which have isolated variables related to the community placement of children indicate that: (a) over half of the children who are released go to self-contained special schools rather than integrated public schools (Wyngaarden, Freedman, & Gollay, 1976); (b) foster care is more successful for severely retarded children than mildly or moderately retarded children (Sternlicht, 1978); (c) lower income families are more likely to accept their own child back into the home after release than higher income families (Bruininks, Thurlow, Thurman, & Fiorelli, 1980); and (d) children who are deinstitutionalized are more likely to be older at the time of initial admission than children who are not released (Wyngaarden, Freedman, & Gollay, 1976).

Reasons for failure of community placement, resulting in readmission of children, include lack of respite care for children in natural or adoptive homes (Pagel & Whitling, 1978) as well as negative community reactions to the presence of mentally retarded children, lack of educational services, and conflicts between natural and foster parents (Sternlicht, 1978).

Both natural families and foster parents caring for released children face problems related to a lack of community support services, including educational programs. Justice, Bradley, and O'Connor (1971) reviewed the experiences of 195 children on leave from Pacific State Hospital. The children ranged in age from 4 to 17, with most falling in the 12-17 year old group. Problems faced by their foster parents included lack of public acceptance for the children, difficulties with schools related to inadequate services, lack of day care and recreation programs, lack of medical and dental care,

conflicts with agencies responsible for placement, conflicts with natural parents, and maladaptive behaviors in the children. These problems, however, can be overcome if community support services are available. When such services are available, there is evidence that foster parents will positively adjust to a child's handicapping conditions (Browder, Ellis, & Neal, 1974). Natural parents also report problems in accepting released children back into their homes, including lack of free time, neglect of other family members, and adverse reactions from relatives, neighbors, and friends (Bruininks, et al., 1980). Finally, families who refused to accept their own children after discharge were more likely to choose institutionalization initially because of a death or illness in the family or concern that the female spouse would have to change or quit a job in order to meet the needs of the disabled child.

Two critical variables which bear on policies affecting deinstitutionalized children are placement stability and amount and direction of placement instability. Placement stability is defined as the percent of children who remain in the educational and residential placement to which they are initially discharged. Placement instability is defined as the percent of individuals shifting educational and residential placement and the degree to which the subsequent placements are more or less restrictive. The only study focusing exclusively on children using these variables is that of Reagan, Murphy, Hill, and Thomas (1980). They examined the post-release histories of 188 mildly and moderately retarded children placed in natural, foster, and group homes. The average age of the children

at the time of placement was 15 years. They found that 18 months after release, most children placed in their natural homes were still there, and only a small number had moved to more restrictive settings. Children placed in foster homes were more likely to have changed placements, usually in the direction of less restrictive environments. Children in group homes were still more likely to have changed placements, with over half moving to more normalizing foster or adoptive care. Unfortunately, the study did not examine specific educational placements in addition to residential settings.

Seltzer and Krauss (1984) have recently examined the residential placements of a sample of 761 children who lived in public institutions in Massachusetts in the period between 1972 and 1976. By 1980, 211 of these children (27.7%) had moved to community residences. Of these, 197 (93.4%) were in group homes or foster homes; and only 14 (6.6%) were in their natural homes (see Table 6.1 in Chapter 6 for a comparison of these findings with an earlier study and with the present study). Of the 540 children who remained in an institution, only <u>one</u> had been recommended for placement in her natural home. Those children who had left were less impaired with respect to mobility, medical problems, and level of retardation, and had fewer behavior problems compared to those children who remained. Children placed in community residences (foster care or group homes) were somewhat older and had a greater need for medical services than those placed in their natural homes, but there were no other significant differences between these two groups. The strongest predicator variables for determining which children remain at an institution and which are placed in communities are (a) the need for

on-call medical support, (b) the number of medical services received, (c) adaptive behavior deficits, and (d) the level of retardation. Given the high frequency of medical needs of children who are likely to remain in an institution, Seltzer and Krauss (1984) recommend the development of specialized community residences capable of providing extensive medical supports in order to facilitate the deinstitutionalization of children and prevent the institutionalization of children still living at home.

In general, follow-up information on children who have been deinstitutionalized is haphazard or nonexistent (Bruininks, et al., 1980). Where such work has occurred, it has not examined the educational programs received by children, and has not determined the extent to which such programs are congruent with the mandates of P.L. 94-142 and state level special education laws. Because the primary location of educational programs for severely handicapped children has been in residential institutions or self-contained day schools (Kenowitz, Zweibel, & Edgar, 1978), and because institutions have been deemed in numerous court decisions to be restrictive and inappropriate places for the provision of educational services, it is critical to examine both the educational and residential status of deinstitutionalized children.

Deinstitutionalization and Community Services for Children in New Hampshire

How Many Children Have Left LSS?

Since 1970, the number of children at LSS has decreased both in size and in proportion to the total resident population. In 1974, for

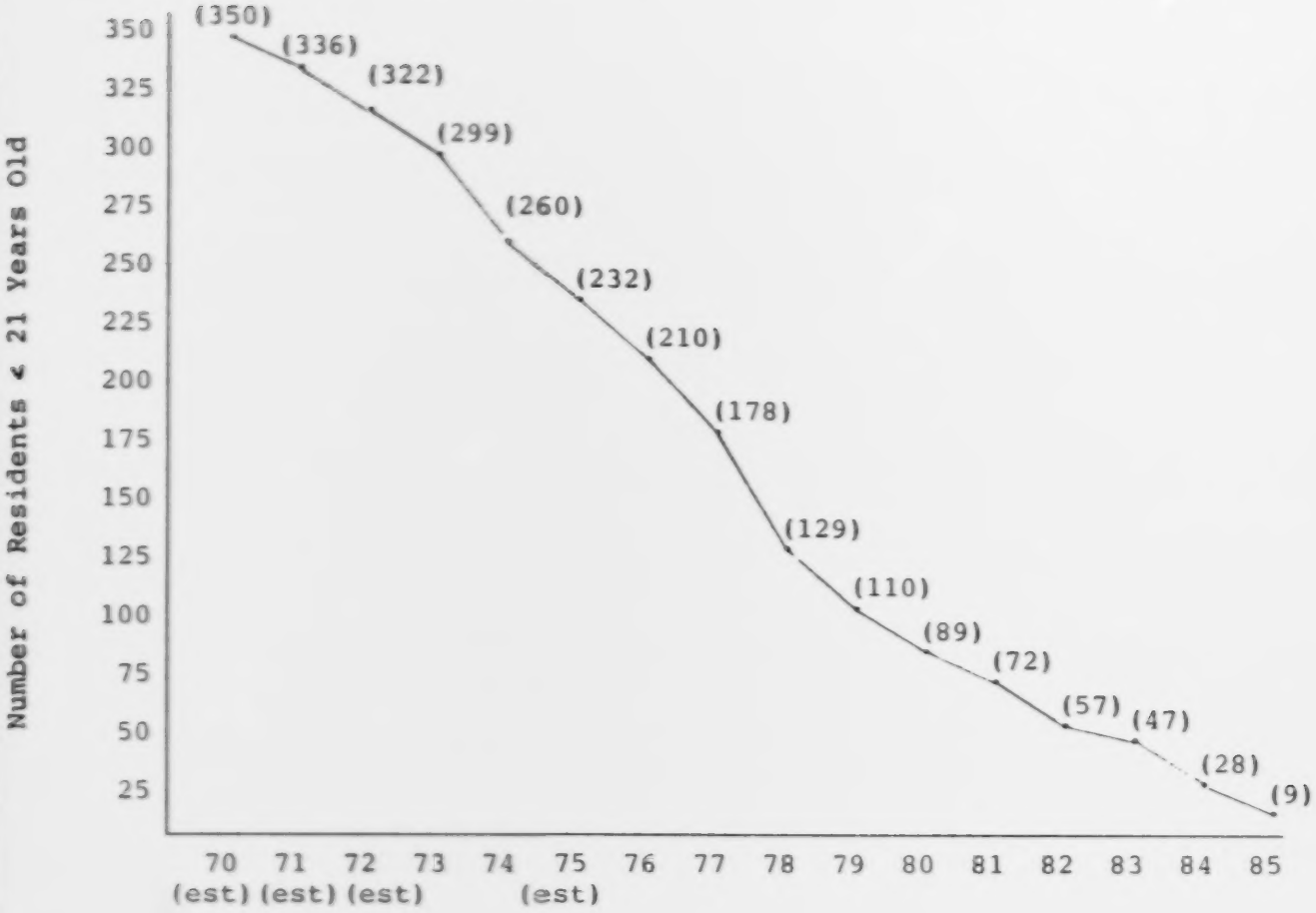
example, children (those below 21 years old) comprised 28 percent of the resident population; five years later the proportion had decreased to 14 percent. By mid-1985, the proportion of children was down to 3.5 percent, half of whom were profoundly retarded. Figure 2.1 indicates the total child enrollment each year from 1970-1985, including those living on campus and those in trial community placements. The 1970-1973 and 1975 figures are estimates based on the assumption that 30 percent of the LSS population was below 21 from 1970-1973, and 26 percent was below 21 in 1975.

Because specific records were not maintained by LSS concerning community placement of children prior to 1976, it is impossible to know what proportion of the decline in children before 1976 is due to placement and what proportion is due to attaining adulthood. Beginning in 1976 however, monthly records are available of community placements and discharges. These numbers are shown in Table 2.1. It is important to note that these are not unduplicated counts. That is, the same child may have experienced both community placement and discharge in the same year, and some children were placed more than once in the same year (or in different years). A very small number of children were also discharged, readmitted, and subsequently discharged again.

During the nine and one-half year period depicted in Table 2.1, there were 90 community placements of children (an average of 9 per year), 35 returns of children to LSS from community placements ($\bar{x}$=3.5), and 61 discharges ($\bar{x}$=6.1). The ratios of returns to placements ranged from a low of 4:13 in 1976 to a high of 11:13 in 1979. The percentage of children placed from the total LSS population averaged

Figure 2.1

Decline in Population of Children at LSS, 1970-1985



[a]Based on data for July 1 of each year, both in-residence and community placement populations

Table 2.1

Children on Community Placement or Discharged from LSS, 1976-1985

Year[a]	Community Placements	Returned to LSS From Community Placement	Discharges	Total Child Enrollment[b]
1976	13	4	17	200
1977	17	6	12	145
1978	11	4	6	120
1979	13	11	2	96
1980	9	7	2	78
1981	6	2	1	65
1982	2	1	2	54
1983	11	0	6	36
1984	5	0	12	21
1985	3	0	1	9

[a]Based on 12-month period ending December 31;
except 1985, which includes data through June 30 only

[b]Includes both in-residence and community placement populations

1.67 percent, from a low of 0.4 percent in 1982 to a high of 2.5 percent in 1977. The number of new admissions to LSS declined over the period from 7 in 1976 to 3 each in 1977, 1978, and 1979, one each in 1980, 1981, and 1982, none in 1983, and 2 in 1984.

Table 2.2 indicates the percentages of the child and adult resident populations experiencing community placement from 1976 to mid-1985. Prior to 1979, adults left at a greater frequency than children. Beginning in 1980, children were placed proportionately more often than adults (except during 1982). Since the beginning of 1983, roughly one-fifth to one-quarter of both the adult and child populations have been placed annually. It appears that this rate may be slowing for adults and accelerating for children in 1985.

It is impossible given the record keeping system at LSS and our lack of access to all files of children who lived there to determine the exact unduplicated number of children who left between 1970 and 1985. However, we can arrive at an estimate based on the data that are available. When we began the clinical reviews in 1982, we arrived at a figure of 226 children who were placed some time after 1970 prior to their 21st birthdays. However, it was soon apparent that many of this group had not actually lived at LSS more than two or three weeks. In the early 1970s, LSS provided the only comprehensive facility in New Hampshire for evaluation of retarded children. Evaluation involved formal admission, so the census in those years included these short-term residents. Although a child would leave soon after admission, no formal discharge occurred until some time later. In some cases,

Table 2.2

Comparison of Child and Adult Community Placement Ratios

Year	Total Child Enrollment at LSS[a]	Number of Child Community Placements[b]	Child CPs as a Percent of Child Enrollment	Total Adult Enrollment at LSS[a]	Number of Adult Community Placements[b]	Adult CPs as a Percent of Adult Enrollment
1976	190	13	6.8%	525	106	20.2%
1977	181	17	9.4%	504	108	21.4%
1978	131	11	8.4%	508	82	16.1%
1979	107	13	12.1%	504	52	10.3%
1980	82	9	11.0%	497	45	9.1%
1981	64	6	9.4%	476	31	6.5%
1982	52	2	3.8%	451	40	8.9%
1983	43	11	25.6%	415	87	21.0%
1984	20	5	25.0%	337	61	18.1%
1985	10	3	30.0%	273	17	6.2%

[a]As of January 1 each year; figure includes in-residence population only

[b]Cumulative figure for 12-month period, January 1-December 31 or 6 months, January 1-June 30, 1985

discharge was not recorded for more than a year after the brief stay, resulting in inaccurate counts of the resident population.

In addition, some children left LSS in the late-1960s, but their placement or discharge was not noted until some time in the 1970s. We did not wish to include these two groups in our sample because (a) the stay at LSS was so brief that it would seem to have little consequence for the education and family circumstances of the child, or (b) the child left prior to the historical period of interest. Eliminating these two groups resulted in a potential pool of 187 children. Three of these children had died at the time the project began, resulting in a potential sample of 184. However, we are not completely confident of the accuracy of this number given our inability to contact each family to confirm the length of residency and date of placement. As will be seen in Chapter 3, we mailed informed consent letters to the last known addresses of the potential sample. Of the 187 letters mailed, 63 were returned by the post office as undeliverable (no such address, addressee doesn't live here, forwarding time expired). Subsequently, we located 11 of this missing group through other means. In the end, we established contact with 74 of the potential group, leaving the remaining 113 unverified in terms of their residential status at LSS and in the community.

Because we encountered several situations in the contacted group where it turned out that records were inaccurate, and two perplexing instances where the parents claimed their children had never been at LSS, our confidence in the 187 figure is low. Our best estimate is that the actual figure is slightly lower, or approximately 170 children

lived at LSS for a significant length of time during the period of investigation and were placed in the local community prior to reaching adulthood.

Where Have These Children Gone?

There has been very little follow-up research on deinstitutionalized children either nationally or in New Hampshire. Recent investigations focussing on children are discussed in an earlier section of this report. In New Hampshire, there has been no systematic effort by LSS staff or state agency staff to document the experiences of children who once resided at LSS. The present study is an attempt to fill this critical knowledge gap, and the work currently underway by James Conroy and Valerie Bradley under contract with the New Hampshire Developmental Disabilities Council will also shed some light on our understanding of the consequences of deinstitutionalization.

Later, we will answer the question at the head of this section in detail. At this point, some general comments are necessary. First, a system of alternative living arrangements located in children's home communities simply has not evolved in New Hampshire. By 1985, there were only 33 children receiving residential care under the auspices of the Office for Community Developmental Services of the New Hampshire Division of Mental Health and Developmental Services (DMH/DS) (Lepore, 1985).

In general, children with severe mental retardation or other major disabilities either live at LSS or remain at home with their families. In New Hampshire, 15 percent of all mentally retarded people who live outside of their natural homes are under 21 years old. Nationally,

24.8 percent of mentally retarded people who live outside of their own homes are children. We seem to rely more on care for children in their natural homes than is the case in other states. In 1982, there were 71 residential facilities for mentally retarded children and adults in the state (Hauber, et al., 1984). It is not known how many of these facilities cared for children, although it appears that very few did so. As of 1985, there were fewer than a dozen residential facilities specifically designed for children, and almost all of these opened within the past three years. In a recent report issued by New Hampshire Legal Assistance, it was asserted that, "Individuals under the age of 21 are experiencing tremendous difficulty in obtaining housing through their Area Agencies [the regional service system for people with developmental impairments]" (Rugg, 1985).

Expenditures for community services have traditionally been below those for institutional services. Recently, however, that tradition has changed significantly. In 1977, New Hampshire spent about three times as much on institutional care and treatment as on community services. That ratio remained roughly constant until 1984, when community expenditures exceeded institutional expenditures for the first time. In fact, New Hampshire's community service expenditures were among the five highest in the United States, based on percentage of personal income and per resident calculations (Braddock, Howes, & Hemp, 1984). These figures are clear signs of an increased commitment to the provision of community-based care and treatment.

However, the vast majority of these services are aimed at adults. Children with mental retardation by and large depend on their families and local school districts for their residential and educational needs. And families and local school districts receive very little outside state or federal assistance in meeting these needs.

In sum, residential and educational services for both children and adults with severe retardation have been delivered primarily in institutional or segregated environments until quite recently. When children left LSS to return to their families and local schools, there was no systematic procedure for keeping track of them. A community-based system capable of meeting the unique residential and educational needs of children did not begin to emerge until the early 1980s. It is in this light that we pose the primary question that has guided our investigation: What are the residential and educational consequences of deinstitutionalizing children with mental retardation? We now turn to that question and the data we have gathered to answer it.

Chapter Three

Locating the Research Population

The process of locating those subjects who met our population criteria described in detail in Chapter Five seemed to present a classic "Catch-22" situation. In order to know who would be included in the study (and therefore from whom we needed to obtain consent), we had to determine which past and current residents of the institution met our specific age and residency criteria. This determination required access to clinical records at the institution. But in order to have such access, we needed prior consent from all those individuals whose records we would examine. The institution had no way of knowing which residents met our criteria, requiring that someone review all client records, including those stored in the state archives. The problem was partially solved by the LSS administration when it agreed to hire one of the principle investigator's graduate students as a staff member of the institution. This person then had access to the records because she was now a legitimate member of the institutional staff. After two months of reviewing the records, she was able to develop a list of those people who we needed to locate. However, she could not share those names with the University research team without the written permission of those involved.

The next step, then, was to have her give the list of potential subjects to institutional staff in its Office of Community Integration.

They agreed to mail letters, including consent forms and an explanation of the study, to all those on the list. As indicated earlier, many of the addresses available from the institutional records were outdated. Of 187 letters mailed to potential members of Population One (those who had left prior to their 21st birthdays), 63 (33.7%) were returned by the post office. After a total of three mailings to locate subjects, 60 letters remained either unreturned by the post office or unreturned by the addressee. There is no way of knowing whether these letters were received and ignored, lost, or received, read and not returned because the parent or guardian did not wish to participate.

Of those that were returned by the parent or guardian, 10 denied consent for their child or ward to participate. The most common reasons for denying consent included current family stress that precluded participation in interviews, fear of intrusive questions, and a misconception that participation in the study would lead either to reinstitutionalization in the case of community residents or to deinstitutionalization in the case of institutional residents. This latter misconception occurred partly because the cover letter sent to the parents or guardians was on institutional letterhead, although the consent documents were on University stationery. Thus, for those parents or guardians who feared that the study meant their child might be recommitted, the letterhead only served to reinforce this notion. We strived to emphasize the independent nature of the study, but parents or guardians were often unable to make the subtle distinction between the state university (acting as an independent agency) and the state institution.

Networking

Given the problems encountered in soliciting consent through the mails, our next step was to develop community networks of people and organizations that could assist us in locating subjects. The networks that seemed to hold the most promise included community agency staff (especially case managers) and parent organizations such as state and local chapters of the Association for Retarded Citizens (ARC). In order to obtain the support and cooperation of these groups, we went through a four-stage process of: (a) telephoning and meeting leaders of the various community groups, (b) arranging time on the group's meeting agenda to describe the study and solicit support, (c) distributing "contact packets" to the group members, and (d) maintaining contact with the group to assure that they followed through on the agreed-upon procedures. The "contact packets" included a one-page description of the study, a list of the personnel involved, an informed consent document, and a self-addressed stamped postcard that parents or guardians could return directly to us to indicate that they would like more information before giving their consent.

This approach was well received by ARC groups. Parents were able to see the potential benefits of the study, although some had inappropriate expectations that participation would lead to better services for their individual children. One father even withheld consent when we explained that we were unable to act as advocates on behalf of his child, whose services he felt were inadequate. Although we were ready to provide names of service providers and advocacy groups when parents expressed such concerns, we had neither the time, the

ability, nor the right to conduct individual investigations during the course of the research. In general, ARCs were enthusiastic about the project and devoted time and energy to mailing the contact packets to members and publicizing the study in their newsletters. Because we often could not directly trace the source of a consent when one was obtained, the number of additional consents resulting from this activity cannot be determined. However, a secondary benefit of this process was that many more people became aware of the study in its early stages. The initial meetings with these groups also led to important discussions about parents' perceptions and evaluation of communitization in its present state. This knowledge was useful in guiding us to more meaningful interview questions, and in analyzing the data to generate policy recommendations. The research process was therefore more grounded as a result of the development of these community networks.

Service Providers as Informants

Developing rapport and support with case managers and other service providers was a somewhat different experience. The case management and community services system in New Hampshire was in its early stages of development when the study began. Many of the staff in these agencies were new to their positions, and many had no previous experience with research projects. This inexperience, combined with the common concern that our study would reflect on their ability to perform their jobs, resulted in some initial resistance. Meetings were arranged with the administrators of the community services to explain the purposes of the study and to describe our expectations regarding access to staff and

records. Additional meetings were held with case managers for the same purpose. At this level, we encountered skepticism and some trepidation. Case managers, who rightfully saw themselves as overworked, expressed concern about our demands on their time. Some questioned the value of research, arguing that our questions were either too general to be of help to them, or that our presence would create problems in their relations with their clients. Many times, case managers and others wanted us to add specific questions or variables that would respond to their immediate concerns. Some of these suggestions were quite helpful, others seemed to reveal underlying fears that our work would result in an evaluation of their performance. After repeated meetings with groups and individuals to clarify the goals and limits of the study, most of this resistance and fear dissipated.

Similar reactions were encountered with institutional staff and public guardians. At the institution, in the early stages of record review and interviews, staff assumed that the study was directly related to the recent litigation that had led to a harsh indictment of the institution. Some staff thought that our workers were attorneys, and many perceived our role as primarily evaluative. After the first month, when we paid a great deal of attention to protocol and hierarchy at the institution, staff relaxed and opened up to us, accepting our presence as routine.

Public guardians, who had legal responsibility for many of our potential subjects, were also skeptical in the early stages. Their concerns focused on informed consent and the intrusiveness of our procedures. As guardians of our subjects, they closely scrutinized

consent documents, requested meetings with us, and questioned our purposes and procedures. They clearly had a protective stance relative to their wards. They also expressed fear that our contacts with family members could interfere with their role as guardians. There was a belief that the parent interviews could result in some parents wanting to re-establish contact with their children, which could possibly lead to tension between the legal guardian and the subject's parents. It was agreed that parents who had not had contact with their children since they left the institution would not be interviewed. For our purposes, they would not be valid sources of data anyway since their contact with their children was minimal. In the end, the public guardians provided consent and were fully cooperative as the study progressed.

In addition to the steps just described, meetings to explain the project were held with parents of children still residing at the institution, state-level administrators in the Departments of Education and Developmental Services, and the state-level committee on PL 94-142 compliance.

Informed Consent

As potential subjects were identified through the third party route just described, the next step was to obtain their informed consent to participate in the study. Research which focuses primarily on children with mental retardation presents some unique considerations in the area of informed consent. On the one hand, people under 18 years old are minors and legally incapable of

giving their own consent, whether or not they are classified as mentally retarded. This group presented no significant problems in obtaining consent. All of our subjects who were still below 18 had parents or guardians who were accessible to us. On the other hand, many of our subjects were no longer minors. Some were still below 21, and therefore viewed as children for the purposes of the study (that is, they were still eligible for educational services under PL 94-142). Most of the remaining group were in their early to mid-twenties. Some of these young adults had been assigned public guardians, and obtaining consent was a straightforward process. But the remaining group had not been adjudicated as incompetent, and therefore they were legally their own guardians. Yet many still lived at home, where their parents acted as their guardians. In fact, almost all of the parents contacted believed that they still had legal authority over their adult children. Even when subjects were no longer living at home, parents viewed themselves as having the right to make decisions for their children.

This situation presented us with an interesting dilemma. Should we take a strictly legal approach and obtain consent solely from the adult retarded person, bypassing the parent, or should we view the retarded person as <u>de facto</u> incompetent and seek substitute consent from a person who had some social and personal responsibility for the individual (in this case, his or her parent or nearest relative)? We opted for the latter choice. We believed that to bypass the role and concern of the parent would unnecessarily introduce confusion and stress. For us to introduce

the notion that the parent no longer had any legal relationship to their child, and that we could enter into their lives without the parents' permission, was seen as intrusive. We were also concerned that we establish positive relationships with parents so they would participate as respondents to our interviews. Because the service providers also seemed to be acting as though the parents were still guardians, we wanted to act in a consistent fashion. Interestingly, none of the state agencies, community staff, or institutional staff raised this issue as a concern. It was one that we identified and resolved internally.

Chapter Four

Fieldwork Methods

The primary methodological approach used in this study was triangulation. Triangulation requires the use of two or more methods to measure the same trait for the purpose of insuring reliable and valid observation and definition of that trait (Campbell & Fiske, 1959; Denzin, 1970). The term triangulation refers not only to the distinctly different methods that are used, but also to the different sources of data used to measure the same trait. That is, multiple tools of measurement are applied to multiple groups of informants.

Recall that the guiding question in our study is, "What are the consequences of community placement of previously institutionalized school-age children?". To answer this question (and the many more specific questions related to it), we wanted to know what factors determined the post-institutional experiences of the research population. Therefore, we considered medical and behavioral descriptions of the children, their diagnosed levels of retardation, pre- and post-institutional experiences in the community service system, family social and economic background, and parent attitudes toward institutional and community care. Table 4.1 summarizes the key traits of interest in the study and the data sources used to examine each of these traits. As can be seen from the table, several several methods were employed, including review of archival data and interviews with multiple informants (parents, case managers, service providers, and ex-residents).

Table 4.1

Data Sources and Types

Source of Data \ Type of Data	Family Background	Reasons for Admission	Medical and Behavioral Characteristics	Community Services		Attitudes Toward Deinstitutionalization
				Residential	Educational	
Institutional Records	x	x	x	(1)	(1)	
Parent/Relative/ Guardian	x	x	x	x	x	x
Case Manager or Service Provider	x		x(2)	x	x	
Ex-Resident		x		x	x	x

Notes: (1) Community services data only available during trial placements prior to final discharge

(2) Only for post-institutional period

Interviews

The interviews were of the schedule standardized type (Denzin, 1970). However, interviewers were allowed some leeway in the order in which they asked the questions and in the phrasing of questions so that the respondent understood exactly what he or she was being asked. At times, the interviewer's role was to record information which was spontaneously offered by the informant before a specific question was even asked, requiring the interviewer to go back and forth in the schedule, according to where a particular item was located. Allowing for this kind of flexibility and spontaneity reduced the reactivity of the instrument.

Face-to-face interviews were chosen over mailed questionnaires because the interviewer could explain and dispel any questions or misconceptions the informant may have had regarding what was being asked, thereby reducing ambiguity and incorrect responses; and the conditions under which the data were gathered became more uniform. Even though there was a great diversity of interviewing conditions because of the idiosyncrasies of families' homes and service settings, the interviewer acted as a constant factor as well as an agent of social control, tending to reduce the amount of interference that might otherwise have been present if the person were simply filling out a questionnaire.

The drawbacks of the interviews are that (a) they are measures taken at one point in time, (b) information is subject to the accuracy of the memory of the respondent, and (c) there is no pre-testing, i.e., there is usually no information about the period of

time prior to the point in time being covered by the interview. In order to compensate for these shortcomings, institutional records were examined which served to provide an historial context to the data we gathered from informants. In this way, archival analysis provided the pre-test information and a more longitudinal perspective than would otherwise be possible was gained.(1)

Another major disadvantage of the interview method is that it is open to recall and viewpoint biases. For example, one parent in his opening statement about his son's educational career, said his son received "no education" and "hardly any services." Later in the interview, however, the father proceeded to tell the interviewer about several schools his son had attended. His opening gambit had more to do with his current frustration at his son's present situation than with his son's educational history, which was the main focus of the interview. Had we not built in reliability checks by asking about education in two different points in the interview, this may not have been revealed.

Because of the many correlates of memory bias and decay--elapsed time, frequency of the event, level of importance or significance to the individual--parents were not asked to provide too many particulars regarding their child's educational experience, only to answer whether their child received educational services before and after going to the institution. Though we asked for the length of

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(1) Copies of all record review and interview protocols are available from the principal investigator.

time the child went to school, these data are less reliable. However, in some cases, parents were able to document this information from their own vast collection of medical and social histories on their children. In other cases, service providers would substantiate the information. Fortunately, when dealing with beaureaucracies, there are records. The field researchers were instructed to encourage the parent or service provider to consult his or her records whenever possible. Often we had to pore over the records ouselves, especially when informants were unable to cull the data for us.

Aside from the temporal drawbacks, the interview was limited in the way questions were phrased. In most portions of the interview schedule, closed-ended questions were asked with multiple choice and Likert-type answers. Parts of our interview contained questions which were duplications of those asked by Conroy and Bradley (1985) in the Pennhurst study. Thus, part of the study replicated methods used by other researchers in related investigations.

Multiple choice questions of the Likert type do not allow spontaneous answers and require the respondent to limit his or her thinking to fit the question. For example, respondents were asked to say whether they "strongly agreed, somewhat agreed, neither agreed nor disagreed, somewhat disagreed or strongly disagreed" with the concept of deinstitutionalization. Often the responses ran something like: "Well, I agree, but only if it means Bill will get one-to-one supervision. In that case, I'm for it." The question as asked does not allow for such qualifying statements.

Though the ability to compare our data with other researchers was gained by merely coding the answers to the questions, we could have lost valuable sources of insight into these parents' true opinions and concerns. Therefore, field researchers were instructed to press the respondents to choose a particular answer, but also to write verbatim the unsolicited comments made by the parents.

Interviews of Parents

Parents of children who have been institutionalized were very important sources of information. Although their information may be distorted by time, emotion, or periods of reduced contact with their children, they still must be recognized as legitimate sources of specific types of data. They knew the child best prior to institutional placement. They often maintained intense interest and some degree of contact with their child during the period of placement, and they often assumed some level of involvement when the child returned to his or her community. The parents' attitudes, resources, and skills thus were important in understanding the communitization process.

Parent interviews had the potential to be highly intrusive and painful occasions. Because of the retrospective nature of the interview questions (e.g., Why did your child go to live in the institution? Who recommended the placement? How often did you visit your child? What are your attitudes toward deinstitutionalization?) painful memories were recalled. Earlier feelings of guilt, anger, or confusion related to placing their child out of the home came back

to the surface, perhaps for the first time in a decade or more. To an unexpected degree, parents readily opened up. Although the experience was obviously a painful one (many cried and openly expressed their pain and anger during the interviews), it also seemed beneficial. Many of the parents said that no one had ever asked them these questions, particularly in a neutral context. Because the interviewers did not represent the service system, their questions provided the opportunity for parents to give information and express deeply-held beliefs without fear of judgment or loss of services for their children. Parents frequently said they were glad that someone cared enough to listen to their stories.

For some parents the pain experienced over the years of caring for their handicapped child precluded their participation in our study. Of the 10 parents who denied consent for their son or daughter to be included, half said it was due to the fear that to do so would create even greater stress for themselves or their children. In some cases, husbands expressed concern for the emotional state of their wives. "She has been through enough. I don't want anything else to upset her." Some parents were concerned that the study would add stress to their children's lives. "She's doing very well now, and I don't want anybody to bother her." "He's lived in a gold-fish bowl long enough. We just want to let things rest at this point." One parent spoke at great length about the stress she and her daughter had gone through. She felt very bitter about her experiences.

She told us, "The quality of her life has improved 100 percent since she left there. You [the researcher] just want to take her back there. I'll never let that happen." This mother's fear that participation would result in reinstitutionalization was not unique. The stress that she and others experienced resulted in significant anxiety about the present and future. This anxiety clearly made them fearful of the consequences of giving consent to participate in the study.

Another clue to the stress of parent interviews came from a father who had initially given consent on behalf of his son, and subsequently gave us permission to interview him and his wife. When the interview began, the father bacame very upset at the personal nature of the questions. "It's none of your damn business! What does this [a question about his occupation] have to do with my son's treatment anyway? Everybody from the secretary up will know my business. That's not confidential. Confidential is when I tell you something and you don't tell anyone else." This man's severely disabled son still lived at the institution, and he greatly feared that his son was soon going to be placed in the community. His anxiety led to an unsuccessful interview, and revealed emotions felt to a lesser degree by many of the parents we interviewed.

Interviews of Community Residents

We asked some of those individuals who left LSS as children to participate in brief face-to-face interviews. The community residents were approached as consumers in the service delivery

system. We wanted to know what they wanted and believed. Where do they want to live? Do they want to go to school? How do they compare life at the institution with life in the community?

The sample of respondents was chosen from a pool of those people who were diagnosed at the institution as mildly or moderately retarded and who did not have a psychiatric diagnosis. Only those individuals who could communicate and understand language were included in this part of the study. Sigelman, et al. (1983) have suggested that verbal interviewing is generally most successful with persons who are moderately and mildly retarded. They note that beginning in the severe range of retardation, verbal interviewing techniques yield unreliable and invalid responses.

In addition to these criteria, screening questions were used, the answers to which could be corroborated by other sources (e.g., parents, case managers). The respondents were asked to tell the interviewer their names, birthdays, gender, home town and whether they had ever resided at the institution. The responses were coded as either correct, incorrect, no response or inappropriate response. If the respondent answered three or more questions correctly, he or she was included in this part of the study. However, whether or not a person answered to criterion, we continued with the interview to explore the reliability of the screening procedure.

Interviews were conducted at the community residences of the subjects at times that were most convenient for them. In most instances, parents were present during the interview. The parents served as both a help and hindrance during the interviews. The

hindrance lay in their tendency to prompt their children to make socially acceptable responses. However, their presence served to orient their child to the situation and to help him or her to stay on task. Parents also helped by their ability to translate our questions into forms more comprehensible to their children, and to assist us in understanding their children's responses.

The guiding question of the interview was, What are the residential, educational, and vocational preferences of people who have left the institution? In order to insure the reliability and validity of our information, questions were asked using multiple formats.

Sigelman, et al. (1983) describe their findings with regard to using four format types when interviewing mentally retarded people. The four types--yes/no, either/or, multiple choice, and open-ended--produce varying levels of reliability. Sigelman, et al. recommend use of either/or questions as a way of reducing problems of acquiescence and selection of the last choice mentioned. (Either/or questions are asked at least twice in variable order to check response reliability). We also relied on open-ended questions to elicit subjective and evaluative comments that would add to our understanding of the experiences and beliefs of each person.

Seven questions were posed with and without the aid of photographs: Would you rather live here or at Laconia State School? Why would you rather live at (previous response)? After naming the

array of pictures,[1] we asked: Which picture looks like where you live? Which picture looks like the place where you would most like to live, if you could live anywhere you wanted? With new pictures we asked: Which picture (happy and sad circle faces) shows how you usually feel? Which shows how you usually felt at LSS? Thirteen questions (about ten minutes) later, we asked again: Would you rather live at LSS or here?

A final, open-ended question asked was: If you could have anything you wanted (in the whole world) what would it be? The purpose of this question was to understand the scope of possibilities envisioned by the respondents, and get some sense of their unfulfilled aspirations and desires. It was also a pleasant way to conclude the interview.

The results of these client interviews are not included in this report. Due to the complexity of analyzing these responses, and the exploratory nature of this research approach, a separate analysis will be developed and published subsequent to this initial description of our findings.

Reviews of Clinical Records

The two most common problems encountered in analyzing institutional and community service records were related to history

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(1) The four pictures were of residential buildings at LSS, a 10-bed group home that did not look like a typical family residence, an apartment building, and a wooden cape single-family home.

and measurement problems (cf. Campbell & Stanley, 1966; Heal & Fujiura, 1984). At a "clerical" level the reliability of the records were affected by the care, accuracy, and completeness with which information was recorded. When very little information was entered for a particular time period, it was not possible to know whether that is because nothing of significance occurred, or staff neglected to make any entries, or significant events occurred that were consciously not recorded (e.g., a resident injury or a questionable behavior modification procedure). This means that the level of analysis must stay at a superficial level. Rich details of a resident's history, details which could have a bearing on later community placement, remained unknown to us unless such details were provided during parent interviews.

At a more substantive design level, history affected the collection and analysis of data because the period of most rapid communitization occurred when changes in federal and state policies were having a direct effect on institutionalized people. The enactment of PL 94-142, The Education for All Handicapped Children Act and PL 95-602, The Developmental Disabilities Assistance and Bill of Rights Act, and corresponding state laws during the mid- to late 1970s, and the results of concurrent litigation have created the need to compare the experiences of those who left in the earlier era (pre-1978) with those who have left more recently. The social and historical context of these two groups was quite different at the point at which they left the institution. In addition, those who left in the earlier period were less severely impaired, increasing

the likelihood that they could successfully "pass" in normal society without formal assistance. This successful reintegration meant that we could not locate these individuals through the parent and service provider networks described in Chapter Three. This is a form of attrition that frustrated us as researchers, but may be a sign of positive outcome for the ex-residents. Although the stories of these successful individuals is an important part of the total picture of the communitization process, it is a part that is largely impossible to explicate. Likewise, case management and client tracking systems have only been developed in New Hampshire since the late 1970s. The accuracy and detail of records is thus quite different for those who entered community programs in recent years.

Closely related to the threat created by history are the issues of changing measurement procedures, changing definitions, and reliance on reported rather than observed data (what Campbell and Stanley, 1966, refer to as threats of instrumentation). Until the late 1970s systematic observation of behavior was not common practice at LSS. The first attempt at complete documentation of all residents' behaviors took place in 1979. Subsequent assessments have been based on the AAMD Adaptive Behavior Scales or other scales with no known correlation to the scales used in 1979. Comparable measures of resident progress are therefore not available. This major problem of instrumentation makes a definitive conclusion about the developmental outcomes of communitization for our sample virtually impossible.

We have also been plagued by the changes in diagnostic labels and codes caused by revisions in the AAMD diagnostic manuals. It was difficult to track precisely the diagnoses of individual residents and ex-residents during the 1970-1984 time period because of these changes. We had to limit the diagnostic descriptors to the general terms mild, moderate, severe, or profound. In addition, it seemed that the level of disability assigned to a particular individual was occasionally independent of IQ score. That is, different clinicians referred to a person as moderately or severely retarded at different points in time even though there was no new assessment of intellectual functioning to verify those judgments. This forced us to rely solely on IQ level, and code retardation level according to AAMD standards. The possiblity for detecting developmental change was therefore limited. The problem was exacerbated by infrequent reassessment during the preiod of institutionalization, particularly in the earlier part of the 1970s.

A final measurement problem was revealed when we compared written data contained in the clinical records with the oral reports of direct care staff. In the process of looking closely at a group of profoundly and multiply disabled children still living at the institution, it became clear that the written behavioral descriptions were deficit oriented. This was due in part to the floor effect inherent in the instruments (and, to some degree, inherent in the attitudes of clinical staff who believed that a profoundly disabled child simply was not capable of manifesting much behavior). When direct care staff were asked to describe the abilities and

limitations of the residents, they made an effort to focus on positive attributes and emerging, albeit subtle, skills. And several staff emphasized to use their concern that the clinicians who conducted formal assessments were not familiar with the residents and the progress they were making.

These threats to validity related to history and measurement required the use of multiple sources of data for each subject. Institutional records, direct care staff, family members, and community-based managers were each used as data sources for a particular person, resulting in a more complete and reliable picture. When conflicting data emerged, it was necessary to follow three basic rules. First, we relied on written records rather than oral recall. This approach was not trouble-free, but it did lead to greater consistency when looking at large amounts of data for large numbers of people. Second, we relied on those people who were closest to the individual subject and who had known him or her over the longest period of time. Sometimes these people were family members, sometimes case managers, and sometimes direct service providers (teachers, therapists, group home counselors). Finally, we used multiple data sources to corroborate each other. Because each data source had its own inherent weaknesses (memory, bias, incomplete records, professional bias, etc.), none was a complete source by itself. In the end, we were forced to make judgments about who or what to believe. Attempts to corroborate through multiple sources led to greater confidence that those judgments were correct.

Case Studies

The other means of obtaining data was the use of case studies. In order to better understand the process of community placement, four cases were chosen from among those individuals who left LSS while still children. One of these cases involves a young woman who was first placed during the time of the study, allowing us to observe firsthand the transition from institutional to community setting. The other cases were of one individual still below 21 and two who are now young adults.

Individuals chosen for the case studies reflect a range of retardation levels from mild to profound and a range of functional abilities from severely behaviorally disordered to severely physically disabled to complete independent functioning. Family circumstances vary as well. The cases were <u>not</u> chosen to be representative of all 68 individuals who left LSS as children. Rather, they were selected because they reflect a variety of positive and negative circumstances that can occur in the community placement process. In two of the cases, the placements were successful and involved few crises or major problems. In the other two, placements were not completely successful, and several crises occurred that serve to illustrate the complex process of deinstitutionalization.

Methods for conducting the case studies included record reviews, interviews with parents and service providers, observations of each individual in residential and educational settings, and an interview of one of the individuals who had been diagnosed mildly retarded.

For the parent and service provider interviews, non-scheduled protocols were used in which a common set of guiding questions were asked but the parents were free to comment on all aspects of their son's or daughter's experiences. In addition to the qualitative data gathered in this manner, the more standardized, quantitative data collected for all subjects were available for the four case study subjects, providing a complete picture of their background and experiences.

To summarize, the methodology used in this study incorporated multiple measures of communitization outcomes. We traced the sequence of residences and educational services obtained before and after a child's residency at LSS. The pre-institutional data were obtained from parents and therefore are subject to the frailties of human memory. Post-institutional data came from parents, service providers, community records and, to some extent, from institutional records (with regard to institutional experiences and trial community placements).

Chapter Five

Characteristics of the Children and Their Families

The samples involved in this study were drawn from the population of Laconia State School residents who were born on or after January 1, 1949 and whose period of residence fell between January 1, 1970 and June 30, 1985. The primary sample of interest included those whose first placement in the community also fell within this period and before the resident's 21st birthday. This group is referred to as Population One (n=68). For comparative purposes, a similar sample was drawn from this age cohort, differing only in that this second group was not placed in the community before their 21st birthday. This group is referred to as Population Two (n=110).

From Table 5.1, it can be seen that a major difference between the two groups is their year of admission to LSS. Though they entered the institution at about the same age, the people in Population Two entered five years earlier; they are, on average, an older cohort. This places Population Two in an historically somewhat earlier period vis-a-vis the trend toward deinstitutionalization.

Table 5.2 shows the distributions of diagnoses for mental retardation at two points during residence at LSS for each population. In general, Population Two is comprised of persons diagnosed as severely or profoundly retarded (86.3%), whereas Population One tended to be diagnosed as moderately to severely retarded (57.4%) when first assessed ($t=-2.69, <.01$; $df=176$).

Table 5.1

Sex and Age Characteristics of Populations One and Two

	At Admission				Mean Age at First Community Placement
	Sex	Mean Age	Median Year	Range	
Population 1	56% male 44% female	8.2	1970	1958-1979	13.0
Population 2	66% male 34% female	7.9	1965	1954-1976	24.0

Table 5.2

Percentages of Mental Retardation Diagnoses for Each Population

	Borderline	Mild	Moderate	Severe	Profound	Unspecified
Diagnosis At Admission*						
Population 1 (n=68)	5.9	7.4	22.1	35.3	22.1	7.4
Population 2 (n=110)			12.7	54.5	31.8	0.9
*(t=-2.69<.01; df=176)						
Diagnosis Closest to Placement or 21st Birthday						
Population 1 (n=39)		5.1	28.2	25.6	33.3	2.6
Population 2 (n=105)	1.0	-	12.4	30.5	56.2	-

We culled the records for a second diagnosis closest to the first community placement for Population One and closest to the 21st birthday of Population Two. (Since Population Two people were still in the institution, for comparative purposes, the 21st birthday was chosen as a reasonable cut-off point at which they would have still been eligible for child-related services had they been placed in the community.) The relative difference in the diagnoses of the two populations remained constant between the first and second diagnoses. However, members of Population Two were more likely to be diagnosed as profoundly retarded at the time of their 21st birthday, compared to their diagnoses at admission.

Behavioral and Medical Characteristics

Table 5.3 compares the two populations on a number of behavioral and medical chacteristics identified in the literature to be particularly salient with regard to communitization. For the most part, the groups were similar. Over two-thirds of each population were able to walk with little or no difficulty, and were able to feed and dress themselves with little or no assistance. Less than half of each group showed occasional or frequent aggression toward others.

Table 5.3

Behavioral and Medical Characteristics

	Population One n=68	Population Two n=110	p
Behavioral Characteristics	% (n)	% (n)	
little or no difficulty walking	76.5 (52)	80.6 (83)	
speech easily understood or slightly difficulty to understand	41.2 (28)	25.9 (28)	<.03
dresses independently or with help	67.6 (46)	66.1 (72)	
feeds self independently	73.5 (50)	73.6 (81)	
toilets independently	52.9 (36)	44.5 (49)	<.20
never or rarely aggressive	50.7 (34)	53.2 (58)	
interacts with others spontaneously or with encouragement	78.5 (51)	67.3 (70)	<.10
extreme unresponsiveness	16.6 (11)	28.1 (31)	<.01
stereotypical behavior	35.3 (23)	44.1 (48)	<.04
some writing skills	29.4 (20)	14.5 (16)	<.01
some reading skills	19.1 (13)	9.1 (10)	<.02
Medical Characteristics			
cerebral palsy	23.5 (16)	30.5 (33)	
significant sensory loss	27.9 (19)	27.2 (30)	
one or more major medical conditions	26.5 (21)	45.5 (50)	<.03

Where the populations showed differences bordering on statistical significance were with regard to toileting ($p<.20$) and in social interaction ($p<.10$). With regard to reading and writing, stereotypical behavior (e.g., non-purposeful handwaving) and unresponsiveness, Population One was, on the whole, rated more positively.

Of Population One, 41.2% were evaluated as having intelligible speech. In contrast, only 25.9% of Population Two were evaluated as having intelligible speech ($p<.03$). The rest of both populations showed severe impairment or no speech.

About 24% of Population One and 31% of Population Two were diagnosed as having cerebral palsy. Only about 27% of each group showed significant sensory (auditory and/or visual) loss.

Although parents did not present medical problems as a chief concern when applying for their child's admission, about 27% of Population One and 46% of Population Two had one or more major medical conditions (e.g., scoliosis). These differences were statistically significant at the .03 level ($t=2.24$; $df=143$).

Data regarding diagnoses, behavioral, and medical characteristics thus indicate that Population Two, those who remained at LSS into adulthood, were significantly more impaired intellectually, communicatively, and socially than Population One. There were relatively few differences with respect to such major physical characteristics as mobility, self-care skills, and sensory abilities.

Cohort Differences

Population One was divided into five time cohorts according to the year in which they first returned to the community for a period of at least 21 days. This was done in order to detect any changes in delivery of services that occurred over the 1970-1985 period and to assess whether or not these changes were related to changes in the sample with regard to such factors as diagnoses, medical and behavioral difficulties and familial socioeconomic background.

Having already noted that the distinguishing characteristics between the two populations had to do with diagnoses, level of speech impairment and number and severity of major medical conditions, it seemed reasonable to examine these characteristics among the five cohorts of Population One.

Over the five 3-year periods, the trend appears to have been that those persons placed in the community were increasingly more severely retarded. Table 5.4 shows that though each succeeding cohort was more developmentally disabled than the previous one, its members were nevertheless placed in the community. For example, the first cohort (placed in the community before 1972) spanned the full range of diagnostic categories from borderline (17.4%) to profound (17.4%) with the greatest number falling in the moderate range (26.1%). In the two most recent cohorts, where placement occurred after 1978, the range spanned mild to profound with the largest clustering occurring in the severe category.

Table 5.4

Community Placement by First Diagnosis

Level of Retardation*	Year of Placement 1970-72	73-75	76-78	79-81	82-85	Total
Borderline (IQ 70-85)	4 17.4	0 .0	0 .0	0 .0	0 .0	4 6.0
Mild (IQ 55-69)	2 8.7	2 18.2	0 .0	0 .0	1 8.3	5 7.5
Moderate (IQ 36-54)	6 26.1	1 9.1	6 42.9	2 28.6	0 .0	15 22.4
Severe (IQ 20-35)	5 21.7	5 45.5	4 28.6	3 42.9	6 50.0	23 34.3
Profound (IQ less than 20)	4 17.4	1 9.1	3 21.4	2 28.6	5 41.7	15 22.4
Unspecified Degree	2 8.7	2 18.2	1 7.1	0 .0	0 .0	5 7.5
n =	23	11	14	7	12	67

*Chi-Sq = 26.411 Sig = .153 DF = 20

Note: Each cell shows the number of persons with column percentage.

Up until 1981, over 70% of the four cohorts did not suffer from any major medical condition. However, after 1982, two-thirds of those children who left suffered from one or more major medical conditions.

With regard to speech impairment and ambulation, analysis revealed no statistically significant differences within Population One across cohorts. However, the 1982-85 cohort did show an indication of greater speech and mobility impairments than previous cohorts. Most of this recently placed cohort had no intelligible speech (83.4%) and half had no independent mobility (50.2%).

Reasons for Admission

In order to discern possible differences between the two populations with regard to circumstances of admission, we examined the LSS records for details on who made the initial request for admission. Table 5.5 shows that requests for admissions were initiated, for the most part, by parents with auxiliary assistance from the children's physicians and social workers. The data indicate that social workers were more active in the admission process with members of Population One than with those of Population Two.

That parents should be the initiators of their children's admission is not particularly surprising, since 83.8% of Population One children lived at home at the time of admission; the remainder lived with foster parents (5.9%) or in other residential treatment centers (10.3%) just prior to admission. For Population Two, 78% lived with their natural parents, 11% with foster parents,

Table 5.5

Requests for Admission Initiated by
Parents, Physicians and Social Workers

	Parents	MD	MSW*
Population 1	86.8% (n=59)	36.8% (n=25)	36.8% (n=25)
Population 2	78.7% (n=85)	36.1% (n=39)	14.8% (n=16)

*p<.002

and the rest in other facilities such as treatment centers, special schools or mental hospitals just prior to admission to the State School.

Table 5.6 shows the reasons for admission to Laconia State School indicated on the intake forms in each subject's LSS clinical record. The percentages do not add up to 100% because as many items as are applicable were selected. The most common reasons for admission were behavior problems, family problems, the depletion of the mother's coping resources, and unavailability of local school or residential programs. Where the two populations differed significantly were in three particular areas: behavior problems, other siblings being affected, and child abuse or neglect. Of Population One, 61.8% of the families complained chiefly about behavior problems, whereas 31.5% of Population Two parents sought admission because of their children's extreme behavior problems. Child abuse and/or neglect was suspected by admitting staff at the State School to a greater degree for families of Population One than Population Two.

These findings are consistent with the assumption that less severely retarded and physicallly impaired children are more difficult to care for because they are more capable of emitting problem behaviors that are viewed as destructive, oppositional or disruptive. A higher frequency of such behaviors would also be expected to correlate with a higher incidence of abuse.

Table 5.6

Reasons for Admission

Reason	Population 1 (n=68)	Population 2 (n=110)	
Behavior problems	61.8	31.5	(t=4.07<.001;df=137)
Medical problems	14.7	9.3	
Legal problems	4.4	0.9	
Recommended by LEA team	4.4	0.0	
Other residence unavailable	16.2	20.4	
Local education unavailable	23.5	18.5	
Child dangerous to self or others	17.6	12.0	
Family financial problems	14.7	6.5	
Recommended by LSS staff	19.1	21.3	
Diagnostic placement	16.2	9.3	
Mother's coping depleted	36.8	37.0	
Family stress	26.5	22.2	
Respite care unavailable	10.3	5.6	
Other siblings affected	10.3	24.1	(t=-2.48<.014;df=171)
Child abuse/neglect	13.2	3.7	(t=2.11<.038;df=93)

In 37% of each group, clinical records showed that parents requested admission of their child because the mother's coping resources were depleted. Yet the need for respite care was reported in only seven records in Population One (10.3%) and six records in Population Two (5.6%). This may possibly be related to the historical context of this concept and to the policy in practice at Laconia State School at the time. As one mother related to us in an in-depth interview:

> [Laconia State School] had a respite program...You could have 30 days a year but it was a one-shot deal. And I thought...who wants to take their kid and dump him at the State School for 30 days? God, I'd've given my eye-teeth for 30 days but I hated to leave her there. If you only took an hour or a day and that was all you wanted, that was it for a whole year! You couldn't split it up...So we didn't use it. ...You just don't take a kid that lives at home and put 'em in an institution for 30 days! ...I didn't need 30 days at one shot.

Another precipitating circumstance was the effect of the handicapped child upon his/her siblings; 24.1% (n=26) of the parents of Population Two complained that other siblings were affected whereas only 10.3% of Population One made this complaint ($p<.014$).

What is particularly noteworthy with regard to circumstances of admission, is that medical problems were <u>not</u> a chief complaint of either population.

Residence at Time of Admission

The service delivery system for mentally retarded people is divided into 12 regional catchment areas. Generally speaking, Population One members tended to live in Regions 3, 7, and 10, i.e., areas around Laconia, Manchester, Derry, Salem, and Plaistow. These regions comprise the central and southwestern regions of the state. Population Two tended to come from the northern, west and southwestern regions, around the towns of Littleton, Bethlehem, Whitefield (Region 1), Keene, Greenfield, Peterborough (Region 7), Manchester (Region 5) and Nashua (Region 6). These differences are consistent with the historical development of the case management system. Children appear more likely to have left LSS if they initially came from a region in which case management was available at an earlier point in time.

We could not determine the region into which members of Population One were placed, particularly in the early and mid-1970s. In general, it is safe to assume that Population One members were returned to their original communities of residence at the time of their first placement out of the institution. This would be particularly true in the period after 1978 when return to the "community of origin" became a regulatory policy.

Family Characteristics

The data for describing the characteristics of participating families in Population One were obtained through the combined reports of parents, case managers and service providers, and review of the Laconia State School records. When there were discrepancies among

these sources, we favored parents' reports except in instances of chronological information, when we gave written documents greater credence than human memory. For example, the occupation the father reported to the intake worker at the time of his child's admission to Laconia State School is deemed more accurate than the father's recall in an interview with one of our field researchers in the present.

Practical constraints required us to select a random sample of Population Two in order to compare family characteristics of the two populations. Sampling procedures consisted of developing an alphabetical list of children in Population Two whose parents had retained custodial or guardianship rights or who had remained closely involved in their children's lives. Population Two members with public guardians, non-related guardians, or who had no on-going contact with their parents were not included in this pool of parent interviews. This process generated a list of 55 potential families. By selecting every third name on the list, a random sample of eighteen families was drawn. Seven additional families were included who had come to us desiring to be interviewed, resulting in a random sample somewhat contaminated by self-selection. If a family was unavailable to be interviewed, the next family on the Population Two list was contacted.

These 25 Population Two families were interviewed using a standard parent interview schedule. The questions were identical to those we asked of Population One except with regard to community placement and discharge. Questions about services and placement were omitted since placement for this group would have occurred <u>after</u> the individual's 21st birthday.

Socioeconomic Status. The Nam-Powers Socioeconomic Status Score based on the 1970 U.S. Census was used to obtain a measure of socioeconomic status for the populations (Miller, 1983:290-300). Fathers' and mothers' occupations at the time of admission and at the time of first community placement or (in the case of Population Two) at the 21st birthday were obtained and then assigned the appropriate Nam-Powers Score. Mothers' work profiles differed dramatically from those of fathers. During their children's admission and first community placement, few mothers were engaged in gainful employment. Therefore, in order to get a picture of their occupational status, it was necessary to look at their employment before marriage and their most recent occupation.

In cases where a particular occupation did not appear on the Census list of occupations, the Hollingshead's Two Factor Index was used and the relative position of the occupation was interpolated. In some cases ambiguity necessitated the datum be coded missing; in cases of retirement or unemployment, no score was assigned and was coded not applicable. In general terms, the Nam-Powers Status Score ranges from 1 to 100 and can be divided, for practical understanding, into the categories shown in Table 5.7.

Generally, both populations can be considered an upwardly mobile group. By comparing the father's occupation at the time of his child's admission with his occupation at the time of the child's first community placement, we found that occupation scores rose. The average Nam-Powers score increased 7.0 points for Population One and 1.9 points for Population Two.

Table 5.7

Socioeconomic Characteristics
of Populations One and Two

	Nam-Powers Occupational Score			
	Father's Score		Mother's Score	
Population	Admission*	First Placement/ 21st Birthday	Before Marriage	Most Recent
One	n=63 45.3 SD=26.3	n=50 52.3 SD=25.2	n=50 42.1 SD=27.8	n=48 42.9 SD=28.2
Two	n=24 58.6 SD=21	n=11 60.5 SD=23.8	n=21 49.3 SD=21.3	n=24 51.0 SD=26.7

*t=2.21; df=85; p<.03

Key to Nam-Powers Status Scores

Nam-Powers Status Scores	Category
1 - 24	Laborer: babysitter, dishwasher, factory worker
25 - 49	Semi-skilled: truckers, carpenters, cashiers
50 - 75	Skilled: sales personnel, clerical workers
76 - 100	Professional: teachers, accountants, technical

Since the number of mothers working at the time of their child's admission or at placement were few, we considered their scores before marriage and their most recent occupation as a means of comparing the mother's contribution to the family's status. Consistent with husbands' scores, wives of Population Two, on the average, had higher scores than did wives of Population One.

Parents in the two populations generally held semi-skilled or skilled jobs. Population One parents held lower status, less skilled jobs than did Population Two parents.

Education. The majority of Population One parents (63.0% of fathers and 79.7% of mothers) completed high school but received no additional formal education. A very few parents in this group (1.5% of fathers and 4.7% of mothers) completed college. Population Two parents were more likely to continue their education beyond high school, with 16.7% of fathers and 4.0% of mothers graduating from college. Fathers tended to have somewhat more education than mothers in both groups. These data are consistent with the previous finding that Population Two parents received higher Nam-Powers scores (i.e., held higher status jobs). Both the socioeconomic data and educational achievement data support the notion that the families of the children in this study generally belonged to lower and middle income groups. Population One children were more likely to belong to lower income families, whereas Population Two children belonged to middle income families, and thus were more representative of the general population.

We should note that we attempted to gather specific family income data from parents to more precisely assign socioeconomic status and compare our subject families to the general population. However, problems related to memory, resistance to disclose such information, and the historical influence of inflation resulted in a judgment that such data were not reliable.

Religion. Of the 56 Population One families who answered our questions about religion, only one family said they had no religious affiliation; 50% of the families identified themselves as Roman Catholic while the rest identified with a specific sect of Protestantism (Congregational, Baptist, and Evangelical comprising the largest groups). We asked, "How important is your religion to you?" and about frequency of church attendance. To the first question, 65.5% (n=38) responded that their faith was either very or extremely important. Of the sample, 32.8% reported attending services once a week and 8.6% reported attending two or more times a week. The majority (51.8%) attend a few times or less per year.

Population Two was comprised of 33.3% Roman Catholics, and 37.5% Protestants (Congregational and Methodist being the largest sects represented). Six persons (about 25%) reported affiliation with smaller Protestant sects such as Seventh Day Adventist, or simply "Born Again Christian"; one person was affiliated with Judaism. Two-thirds of Population Two stated that their religion was very or extremely important, with 41.7% attending services at least once a week and 37.5% attending only a few times or less a year.

Race and Ethnicity. As is typical of New Hampshire, the families were racially homogeneous. Seventy-four percent and 15.5% of Population One considered themselves White Americans or of French Canadian or French origin, respectively. Population Two consisted of 70.8% White Americans with another 20.9% claiming French Canadian or French identification. The remaining groups in both populations were White with various native American or European ethnic origins. There were no black families.

Family Size. The average household for both populations was comprised of two natural parents, the child in our study, and three other siblings. Of the 58 Population One families we interviewed, twelve reported that they had at least one other developmentally disabled child in addition to the one in our study. There were three families who had 2, 3, and 4 disabled children, respectively, in addition to the one in our study. Of the subsample of Population Two families (valid n=24), two parents reported they had one other disabled child who also went to LSS.

In sum, then, our participating families typically consisted of two natural parents, four children, one of whom was developmentally disabled and had spent several years at Laconia State School. The families were of Western European stock, of average education, upwardly mobile, with fairly strong religious ideals.

Sample Characteristics and Selection Bias

Due to the nature of sample selection described in Chapter Three, we cannot claim that the members of either Populations One or Two are representative of the total group of children who lived at Laconia State School between 1970 and 1985. Based on the high rate of outdated addresses, it would seem that the children we were unable to locate lived in relatively transient families. Because these children did not surface when we "networked" the parent organizations, service providers, and public guardians, we assume they are either no longer living in New Hampshire or are not participating in the service delivery system for developmentally disabled children and adults. To the extent that the latter option is true, the missing cases are likely to be less impaired (and therefore less in need of services) than those we did locate. These missing individuals may well be "passing" in society as normal citizens with successful jobs and families. On the other hand, if they simply moved out of state, this is consistent with the notion of transiency. A third explanation is that some of these individuals are in segregated human service systems that we did not directly investigate (e.g., prisons, nursing homes).

It is impossible to know how the people we did not find are similar to or different from those we did locate. Our best guess is that these missing cases lived in relatively transient homes, did not leave behind any record of wherre they moved, were unable to understand our consent letters if they actually received them, and were relatively capable of independent functioning. We interpret

these characteristics to mean that those we located are generally from more stable families that could understand our request for subjects and are probably more disabled than those we did not locate. The patterns of transiency and lack of response to the consent letter may reflect a less educated and lower income group. Therefore our best guess as to the direction of bias in our sample (Population One) is that it is somewhat more impaired and from a relatively higher SES group than would be true for the total group of children who left during this time period.

Chapter Six

Residential Placement Outcomes

In this chapter, we will describe the places that children lived after they left LSS, how often they moved from one place to another, the kinds of services they received in local communities (other than educational, which will be described in Chapter Seven) and the differences in residential arrangements associated with the year in which children left the institution.

Type and Stability of Residential Placements

When children leave a public residential facility such as LSS, they either return to the family homes from which they were originally placed, the home of a foster or adoptive parent, a group home, another institutional setting, or some other facility. The few studies that have examined this variable in other areas of the country have found that the percentage of children who return to live with their natural families varies from 6.6 percent (Seltzer & Krauss, 1984) to 59 percent (Wyngaarden & Gollay, 1976). Table 6.1 indicates the types of residential placements found in the present study and the two other major studies that included children. As can be seen, just under half of our sample (46.3%) returned to live with their natural families when they first left LSS. In general, our findings are more similar to Wyngaarden and Gollay's (1976) than Seltzer and Krauss' (1984) more recent work (both of these comparison studies were based on data from the state of Massachusetts). Table 6.2 indicates the specific breakdowns of residential placements for our sample of 68 children.

On the average, children remained at their first community placement for 3.4 years, although the actual length of stay varied widely from one week to 14 years (s.d.=3.9 years). Approximately one-fourth (25.4%) of the initial placements lasted less than six months. Just under one-half (46.3%) were less than one year in length. Slightly over one-quarter (26.8%) of the placements remained constant between one and four years. Seven of the initial placements (10.4%) lasted over ten years. Although the number of subjects is too small to allow statistically defensible statements, it appears that children who left LSS early in the period of investigation (1970-1972) and during the period of litigation at LSS (1979-1981) stayed in their initial placements for shorter periods of time than those who left during other periods.

Twenty-one children, or 31.3 percent of the sample, returned to LSS from their first community placement. The reason for these failures in community placement, in the order of frequency with which they were cited, include:

Child's behavior was too extreme	65 %
Parents requested the return	60
Social support services were not available	30
Crisis occurred in the residence	20
Marital problems in the residence	14.3
Insufficient finances in the residence	10
Child's medical needs were too extreme	5

Table 6.1

Comparison of Children's Residential Placement Outcomes from Three Studies

	Type of Placement			
Investigators	Natural Home	Foster Care	Group Home	Other
Wyngaarden & Gollay (1976)	59%	21%	15%	5%
Seltzer & Krauss (1984)	6.6%	93.4%[a]		
Mallory & Herrick (1985)	46.3%	17.9%	19.4%	16.4%

[a]Foster care and group home percentages combined

The precentages indicate the frequency with which these reasons were cited by parents and service providers. Respondents could select as many reasons as were appropriate.

When children returned to LSS from their first community placements, they remained at the institution for an average of 1.5 years.

Of the 68 children in our sample, 34 (50%) moved at least once after their initial placement. Table 6.2 shows that these children were less likely to live with their natural families in the second placement and more likely to live in another residential institution (e.g., Crotched Mountain Rehabilitation Center, New Hampshire Hospital, Cedarcrest). Periods of residence at a second community placement averaged 3.6 years (s.d.=4.0). Six children of the 34 who had a second placement returned to LSS from this placement (17.6%). In these cases, extreme behavior problems were cited as the primary reason for the return, as was the case in returns after the first placements. Other reasons for return were cited very infrequently. Those children who returned to LSS after a second community placement remained at the institution for an average of 2.1 years (s.d.=2.5).

Of the 34 children who moved at least once after leaving LSS, 19 (55.9%) moved again (or, 19 out of the sample of 68 [27.9%] moved two or more times after leaving LSS). Table 6.2 indicates that these children primarily lived with their natural families or in group or foster homes. The average length of stay in the third residence was 3.0 years (s.d.=3.4). Only one child returned to LSS from the third community placement, due to behavior problems which local services were not capable of addressing.

Only 6 children moved three or more times after they left LSS (8.8% of the total sample). Although the numbers are too small to be reliable, it appears that placement with natural families diminishes as children spend a greater length of time outside of the institution and use of group homes increases. The average length of stay in the fourth residence was 3.75 years (s.d.=3.5). No child returned to LSS during the fourth placement.

It is interesting to note from Table 6.2 that very few children in our sample lived in geriatric nursing homes after leaving LSS, relatively few lived in another institutional setting, adoptive care is rarely used for deinstitutionalized children, and four individuals lived independently for some time. All the data in Table 6.2 are based on the experiences of sample members before their 21st birthdays.

Characteristics of Residential Placements

Size of Residence. During the first community placement after deinstitutionalization, half of the children (50.8%) lived in a home or facility with four to six residents (including the sample child and all other children and adults present). Almost a quarter of the children (23.7%) lived in a placement with 7 to 10 residents. Four of the children (6.8%) lived in a facility with more than 15 residents. Nine of the children (15.3%) lived in a home with only one to three residents.

During the second placement, experienced by 34 members of the sample, fewer children lived in settings of four to six residents

Table 6.2

Community Placement Types

Type of Placement	First Placement (n=68)		Second Placement (n=34)		Third Placement (n=19)		Fourth Placement (n=6)	
	n	%	n	%	n	%	n	%
Family Home	31	46.3	8	23.5	7	36.8	1	14.3
Group Home	13	19.4	7	20.6	4	21.1	2	28.6
Foster Home	12	17.9	5	14.7	3	15.8	0	0
Residential Institution	5	7.5	6	17.6	1	5.3	2	28.6
Adoptive Home	1	1.5	1	2.9	0	0	0	0
Nursing Home	0	0	1	2.9	0	0	1	14.3
Independent Living	0	0	2	5.9	2	10.5	0	0
Other	5	7.5	4	11.8	2	10.5	0	0

(25.0%) and settings of 7 to 10 residents (9.4%). More children lived in small residences of one to three people (21.9%) and in large residences of more than 15 (43.8%).

Children were fairly evenly distributed among residences of various sizes if they went to a third community placement, with less reliance on large settings of more than 15 people (15.4%). However, for the six children who experienced a fourth placement, half were in facilities with more than 15 residents, one-third in settings of 4 to 6 people, and the remaining child was in a small setting of less than 4 people.

By way of comparison, a 1979 survey conducted by the New Hampshire Division of Mental Health/Developmental Services, referred to as "Search and Find," determined that 49 of 116 (42.2%) previous residents of LSS were living in community facilities with 9 or more residents. This survey included both children and adults.

Age-Mix. During the first community placement, of those children who did not live with their natural families, 10 children lived in settings where all the other residents (except the staff) were below 21 years old. An equal number (10) lived in facilities with some children and some adult residents. Five children lived in settings where all the other residents were adults. Data on facility size were not available on the remaining 7 children. As children changed placements, there was greater reliance on adult-only facilities (50% of all children who had four or more placements lived in such settings), which probably reflects the fact that these children were close to adulthood themselves by this point in time.

Services Received During Community Placements

For each of the 68 children in our sample, we assessed the type of services received after community placement. The following discussion will be focused on services other than educational ones, which will be reviewed in the next chapter. Here the emphasis is on medical, therapeutic, vocational, and social services. We also determined who paid for these community services--the child's parents or some other source. Table 6.3 indicates those services received during the first and second community placements and who paid for them. Because the numbers are relatively small, information on services during the third and fourth community placements (n=19 and 6, respectively) is not included here.

Several conclusions may be drawn from Table 6.3. First, parents have generally not been required to pay for the non-educational services their children received in the communities in which they were placed. The major exceptions are medical diagnoses, medication, special dietary programs, and respite care during the first community placement. By the time children moved to a second community placement, which occurred for half of the sample, parents paid for local services very infrequently. This means that the parents of the children in this sample, who were from a relatively low socioeconomic group (see Chapter Five), were not burdened with the additional responsibility of paying for services for their deinstitutionalized children, particularly if their children experienced more than one community placement before their 21st birthday.

Table 6.3

Community Services - Frequency and Payment

Type of Service	Percent of Sample Receiving Service		Percent of Parents Who Paid for Service[a]	
	1st CP (n=63)[b]	2nd CP (n=28)[b]	1st CP (n=63)	2nd CP (n=28)
Medical				
Diagnosis	69.8%	75.0%	33.3%	14.3%
Psychotropic Medication	27.0	14.3	47.1	0
Nursing Care	41.3	50.0	0	0
Special Diet	23.8	32.2	13.3	11.1
Surgery	15.8	10.7	50.0	0
Dental	14.2	17.9	55.6	0
Therapeutic				
Occupational Therapy	47.6	35.7	0	0
Speech and Language Therapy	58.7	75.0	0	0
Physical Therapy	36.5	25.0	0	0
Counseling	28.6	14.3	0	0
Audiology	31.8	39.3	5.0	0
Habilitative				
Day Habilitation	42.9	46.4	0	0
Behavior Modification	49.2	50.0	0	0
Adaptive Physical Education	33.3	32.1	0	0
Recreation	60.3	53.6	0	6.7
Social Services				
Case Management	52.4	60.7	0	0
Public Welfare	65.1	53.6	NA	NA
Parent Counseling/ Family Therapy	33.3	35.7	0	0
Respite Care	20.7	21.4	15.4	0
Transportation	74.6	82.1	2.1	8.7
Vocational				
Prevocational Training	28.6	39.3	0	0
Work Activity Program	9.5	10.7	NA	NA
Sheltered Workshop	20.6	14.3	NA	NA

[a] Includes out-of-pocket and private insurance payments

[b] Data on services received by 5 children in first community placement and 6 children in second community placement not available

More than one-third of the children did not receive medical diagnostic services during their first community placements. Recalling that the average length of these initial placements was 3.4 years, this indicates that preventive health care services were not available for a considerable period of time to significant numbers of a population that we can assume was in need of routine medical care. The record improved somewhat for those children who went on to a second placement, but the proportion receiving diagnostic services (approximately three-fourths) still raises some concerns. Relatively few children received psychotropic medications (e.g., tranquilizers, barbituates, stimulants, antidepressants, etc.) during community placement. Although half of the parents initially bore the burden for paying for these drugs, all children receiving such medications during their second placements did so without their parents having to foot the bill.

The percentage of children receiving dental care was strikingly low. Assuming that everyone requires at least annual preventative check-ups and routine prophylaxis, the members of our sample were at very high risk for undiagnosed and untreated dental problems. This finding raises questions of the availability of dental care for children with mental retardation.

Therapeutic services appeared to be available in local communities to most deinstitutionalized children. Our data do not allow us to determine the extent to which children in need of such services did or did not receive them. However, the most commonly utilized therapies for children with mental retardation were provided

to one-fourth to three-fourths of the sample. Speech and language services were provided most often, which is appropriate given the nature of the population as described earlier. The fact that utilization of occupational and physical therapies declined during the second community placement may be cause for some concern. The relatively low use of counseling services probably indicates the lack of availability of such services rather than lack of need, particularly in light of the finding that most community placement failures occurred due to extreme behavioral problems.

Habilitative services were provided to one-third (in the case of adaptive physical education) to three-fifths (recreation) of our sample. Some of these services were provided in school settings, others in residential and vocational settings. Day habilitation is commonly an adult-oriented service in New Hampshire, but the other types of services listed here would be appropriate for children as well as adults.

In the social services arena, we found that case management was provided at some level to over half of the sample. It is important to point out here that formal case management services were not instituted in New Hampshire until the late 1970s, and it is only quite recently that such services have been made available statewide. During the period of implementation of case management, there was a good deal of confusion over the eligibility of children for such services. Some regional area agencies chose to provide case management to children; others chose not to. Of those children placed in communities since 1982, <u>all</u> have been assigned a case manager, indicating increased availability of this important service.

Upon initial community placement, about two-thirds of the sample received some form of public assistance (e.g., Supplemental Security Income, Aid to the Permanently and Totally Disabled). Given the low socioeconomic status of their families, this assistance was probably a necessary means for community survival. Because Medicaid eligibility in New Hampshire is limited to those people who are receiving another major source of public assistance, this service is important not only for economic survival, but to attend to health needs as well. The fact that one-third of those in first community placements and almost one-half of those in second placements were not receiving public assistance may indicate that some children were not receiving the benefits to which they were entitled. This interpretation is supported by the earlier finding that a significant proportion of the sample did not receive routine medical diagnostic and dental care.

Support for families of deinstitutionalized children was also not widely utilized, either because it was not available, families did not choose to use it, or they were not aware of its availability. In light of the high levels of stress associated with the physical and/or psychological reintegration of a child back into the family after a period of institutional residence, we would expect the need for counseling, therapy, and respite care to be higher than the usage levels indicated in Table 6.3. Here again, as with case management, family support and respite care are recent components of the service delivery system. Some area agencies have chosen not to pay for respite care for clients under 21 years old, while others have.

Schools have not taken up the slack here. Parent counseling, which is identified as a related service under state and federal special education laws, is very rarely incorporated into Individual Education Plans. In general, families whose children have left LSS have received little psychological or emotional assistance from formal service providers. Chapter Eight will elaborate on these issues.

Vocational training services were not widely used by the sample of children we studied. This is not surprising given the age levels of the sample and the fact that most vocational opportunities are aimed at an older population. There was some decline in the use of sheltered workshops for those children who moved to a second community placement. Prevocational training, which would be appropriate for most of the members of the sample, was not provided to a large degree. Although the classification of services was a problem throughout the study, we also found that vocational special education, which could be the same as prevocational training or something different, depending on the informant, was used rarely by the members of the sample (see Chapter Seven).

Effect of Time on Residential Placements

In Chapter Five, the characteristics of the total sample were described with respect to membership in various time cohorts. As indicated, the cohorts were created in order to understand the relationship of the date of community placement to the outcomes of placement. We assume that children who left at different points in time during the period of investigation experienced different

residential and educational circumstances in their local communities. Public policies changed, the availability of services changed, and the technology for treating severely handicapped children changed. The research question of interest here is, Are these historical changes manifested in the types of residential placements experienced by children, and in other variables associated with placement? There is some evidence that the consequences of community placement are subject to these historical factors.

Type of Community Placement. From the earlier discussion, we know that 46.3% of the sample lived with their natural families when they first left LSS. The large majority of this group left in the earlier years of the deinstitutionalization movement. For example, of the 31 children who returned to their own homes, 45.2% left LSS between 1970 and 1972. Only three children (9.7%) who were placed with their own families left LSS in the period after 1978. Of the 12 children who were placed in a foster home, only one left LSS after 1978. On the other hand, of the 13 children placed in a group home, almost all (84.6%) left LSS between 1979 and 1985. Thus, children who left LSS in the period of most rapid change in social policy were less likely to return to their natural homes or be placed in foster care and more likely to be placed in a group home. Two factors contribute to this finding. First, children who left in recent years were more severely handicapped than those who left earlier. Their more intense treatment and management needs may have acted to decrease the ability of families, either natural or foster, to provide care within a normal setting. In addition, the availability of group homes

increased significantly during this period, creating more options for families than existed in the earlier part of the decade.

Length of Stay. Although the average length of stay in the first community residence was 3.4 years, almost half of the total sample (46.3%) remained at their first placement less than one year. Initial placements of less than one year were experienced more often by those who left after 1978 (57.9% of all children who left after 1978) than those who left between 1970 and 1978 (41.6%). Caution in interpreting these data is important. Shorter periods of residential stay for those who have left more recently are in part due to the shorter time since placement, not necessarily due to a less stable pattern of placements in recent years. On the other hand, increased availability of placement options in recent years may create greater movement from one placement to another until the most appropriate alternative is found. The data do not support this second hypothesis because only 2 members of our sample who left LSS since 1978 have had a second community placement. In general, there is little difference in length of stay at community placements across the various time cohorts, when the period of time between initial placement and the present is taken into account.

Size of Community Residence. Size of residence seems to have a greater association with time of placement than the preceding variable. Of those children placed prior to 1979, 75 percent went a home or facility with six or fewer residents. On the other hand, only 47.4 percent of those placed in 1979 or later went to a

comparably sized residence. The remainder, 52.6 percent, went into a facility with 7 or more residents. Three children, or 15.8 percent of those who left since 1978, were placed in residences with 11 or more others; and an equal number went into homes with fewer than four residents. Children who left over the past six years were more likely to enter into placements with more than 6 residents; children who left between 1970 and 1979 were more likely to be placed in facilities with six or fewer residents.

Rates of Return. The overall frequency of unsuccessful community placements resulting in returns to LSS was 31.3 percent for the sample. Here we can see a dramatic change associated with time. Of the 21 children whose placements failed, 90.5 percent (n=19) left LSS for the first time prior to 1979. Only 2 children (9.5%) in our sample who left between 1979 and 1985 returned to LSS after a period of community residency. The highest period of returns occurred in the 1976-1978 period, when an equal number of placements and returns took place. The lowest period of returns is the most recent, when only one out of twelve of the children we have followed since 1982 has returned to LSS. If we examine returns from a second community placement, the pattern is equally strong. All returns to LSS from the second placement occurred in the period prior to 1979.

Community Services. Table 6.4 presents information on services received by children who left LSS before and after 1978. Statistically significant differences, based on chi-square analyses, are found for psychotropic medication, occupational therapy, speech

and language therapy, physical therapy, and case management. Increased use of psychotropic medication is due in part to the increased level of disability and presence of other medical conditions, such as seizure disorders, in the group of children who left the institution in more recent years.

The three therapies commonly provided in schools and community agencies all increased considerably, to the point where three-fourths or more of the group who left after 1978 received such services. Again, this is due in part to the lower functional abilities of the children who left. In addition, the availability of such services has increased notably in recent years in New Hampshire.

As would be expected given the earlier comment on the development of case management in local communities, far more children received this service if they left after 1978. However, a few children who left in recent years still were without a case manager. Their severe levels of disability, the likelihood that they would not live at home, and the sparcity of alternative living arrangements appropriate for children are factors that make the provision of case management a critical issue for this group.

Other service areas, included in Table 6.4 but not described here, did not show statistically significant differences for the two time cohorts. In two areas--vocational training and family support, including respite care--this creates some concern. Prevocational training, including vocational special education, would seem to be an important service for the sample, especially because most of the

Table 6.4

Frequency of Selected Services
Pre- and Post-1978

Type of Service	Percent of Sample Who Received Service: Initial Placement 1970-1978 (n=44)	Initial Placement 1979-1985 (n=19)	Level of Significance
Medical Diagnosis	63.6%	84.3%	ns[a]
Psychotropic Medication	18.2	47.4	x^2=7.4,df=2,p=.024
Occupational Therapy	31.8	84.2	x^2=12.6,df=1,p=.000
Speech and Language Therapy	47.7	84.2	x^2=5.9,df=1,p=.015
Physical Therapy	20.5	73.7	x^2=14.0,df=1,p=.000
Case Management	38.6	84.2	x^2=9.3,df=1,p=.002
Public Welfare	56.8	84.2	ns
Prevocational Training	25.0	36.8	ns
Respite Care	18.1	26.3	ns

[a] Not significant

children left ISS during their early to mid-teen years. Preparation for success in an independent or supported work environment needs to begin well before a student "ages out" or graduates from secondary school. Although most of the children who left after 1978, and all those who left after 1981, are classified as severely or profoundly retarded and multiply handicapped, this does not necessarily preclude the need for some level of vocational training.

There were also no significant increases in the use of family support, including counseling and respite care. This finding is confounded by the fact that far fewer children who left after 1978 went to live with their natural families, but this may be an indication of a cause and effect problem. That is, the lack of such services may have prevented families from accepting their children back into their homes.

Finally, there were no significant differences between the two time cohorts relative to who paid for community services. In spite of the fact that mandates for universal and free services were not in place until recent years, most parents did not have to pay for services regardless of when their children left the institution. Sources from public welfare agencies, public health agencies, and local schools assisted families with payment throughout the period of investigation. Given that most of the families were of a relatively low socioeconomic status, their eligiblity for such subsidies may have been higher than that of the general population.

Summary

These findings suggest a relatively stable pattern of community placements for children. Once children leave LSS, they either return to their natural families or live in some substitute care arrangement. In recent years, as is the case nationally, children have been less likely to be placed with their families and more likely to enter into a group home. Half of the sample experienced more than one community placement; just over one-quarter moved two or more times. Children tended to stay in their respective placements for an average of three to four years. However, almost half of both the first and second community placements lasted one year or less. Residential stability, which we can arbitrarily define as staying put for at least a year, therefore, was experienced by about half of the sample. The other half moved within a year's time, but then tended to remain in one place. Most children (66.1%) were placed in homes or other facilities with six or fewer residents, approximating a family-like size more than would placement in a larger facility.

A significant number of placements were unsuccessful, defined by the need to return the child to the institution. However, the large majority of these unsuccessful placements occurred early in the period of deinstitutionalization. In recent years, almost no children who left LSS have returned.

Use of community services varied considerably for the sample. Therapeutic services were used most often, medical and habilitative services were used sporadically (depending on the specific service), and social and vocational training services were used infrequently

with the exception of case management and welfare. In general, use of services increased considerably for those children who left LSS after 1978, compared to those who left in the earlier period. Parents rarely were required to use their own financial resources to pay for the cost of these services, with some exceptions in the area of medical services. With this picture of the residential experiences of deinstitutionalized children in mind, we now turn to the educational experiences of our sample.

Chapter Seven

Educational Service Outcomes

This chapter focuses on the types of educational placements and services received by children after they left Laconia State School. Because social policies affecting children have emphasized educational rather than residential programs, the data presented here provide an opportunity to more closely analyze the impact of changes in such policies. Other investigations of the consequences of deinstitutionalization have rarely included variables related to educational services.

The findings of the present study are descriptive of the experiences of the sample of 68 children who left LSS between 1970 and 1985. Generalizations to the total population of children who were deinstitutionalized from LSS or from institutions in other states during this time period cannot be made based on these data. In addition, an assessment of the quality of educational services is not possible given the resources available to the study. However, some information on the quality of education for severely handicapped deinstitutionalized children has recently been published by AGH Associates (1985). Those findings will be discussed briefly in light of our own data.

As with residential variables discussed in the previous chapter, location, type, and stability of educational services, as well as the effect of historical time, are described below. Data on education received prior to admission to LSS and the frequency of formal school-parent disputes concerning the provision of an appropriate education will also be presented.

Education Received Prior to Institutional Placement

Less than half of the sample children received any education prior to placement at LSS. Two children received some type of early intervention services as infants or toddlers. Six children attended private preschool programs for an average of 1.67 years. An additional eleven children were in a specialized preschool setting for handicapped children for an average of 2.16 years. One child attended a Head Start program for less than one year. Four children received day care services before placement. Only three children attended a kindergarten program.

Twelve members of the sample attended a public elementary school prior to placement, for an average of 2.76 years (range .10 years to 7.00 years, s.d.=2.34). Fourteen children were enrolled in a private school before admission to LSS for an average of 3.43 years (range .50 to 10.00, s.d.=2.82).

Some children attended more than one of the above mentioned programs. An unduplicated count shows that 18 children had a preschool experience (early intervention, public or private preschool, day care, specialized preschool, or kindergarten). Twenty-four children attended public or private elementary or secondary school. When cases with missing data are excluded, this means that 30 percent of the sample had a preschool experience and 40 percent attended an elementary or secondary program. Nine children (15 percent) attended both preschool and school-age programs.

In general, specialized preschool services were rarely utilized. Children were more likely to receive elementary school services,

although most of the sample was admitted to LSS before they would have reached the third grade, given the average age of admission of 8.16 years.

By way of comparison, members of Population Two, those who remained at LSS into adulthood, were equally likely to have received some sort of preschool service (32 percent of a randomly selected subsample of 25 out of the 110 total in Population Two). Five members of this subsample (20 percent) received elementary or secondary education, only half the proportion of Population One receiving such services. This is consistent with the finding that Population Two members were more severely handicapped and entered LSS at a slightly younger age.

Post-Institutional Experiences

Types of Educational Placements

When children returned to local communities after a period of institutionalization, they either received no educational services (22.4 percent of Population One; n=15) or were placed in specialized settings with other handicapped children. Table 7.1 indicates the various educational placements assigned to 52 children who received some type of educational programming after community placement (educational placement data for one case were unavailable). The large majority of children (82.8 percent) were placed in a self-contained classroom or school when they first left LSS. All other possible placements were used very rarely. However, for those

Table 7.1

Types of Educational Settings

Type of Setting	First School[a] (n=67)	Second School (n=28)	Third School (n=12)
No school assigned	22.4%	NA	NA
Regular classroom, with resource room	1.9	0	25.0%
Self-contained classroom, regular school	15.4	32.1%	33.3
Special school, non-residential	67.4	39.3	25.0
LSS, day only	3.8	7.1	0
Special school, residential	1.9	10.7	8.3
Home instruction	1.9	3.6	0
Residential institution	7.6	7.1	8.3

[a] Percentages shown based on 52 children who were assigned to a school after they left LSS (excludes 15 children who did not receive any educational placement)

children who changed educational placements, there was increased use of the less restrictive environment of a regular classroom with resource room support. Relatively few children attended residential schools, received homebound instruction, or relied on institutionally-based education programs.

Of the 52 children who received any educational placement, 61.5 percent (n=32) attended programs in the school districts in which they lived. Out-of-district placement was used for the remaining 38.5 percent (20 children). Table 7.2 presents these data, and traces changes in educational settings in relation to changes in residential placements. If a child experienced a second residential placement, he or she was less likely to receive local, in-district services. Children who moved to a third residential setting were less likely to receive any education. However, those who were enrolled in school were more likely to attend a local, in-district program. These differences indicate trends, but they are not statistically significant.

The types of services received during community placement were described in the previous chapter. In addition to the educational and therapeutic services discussed earlier, there are three additional areas worthy of mention here. First, vocational special education, as differentiated from other types of out-of-school vocational training or employment, was utilized by relatively few children. During the first and second community placements, only 7.9 percent and 10.7 percent of the sample, respectively, participated in vocational special education, although the average age of the sample

Table 7.2

Relationship Between Educational Program Location
and Changes in Community Placement

	Community Placement		
Program Location	First (n=67)	Second (n=34)	Third (n=19)
No school assigned	22.4%	20.6%	36.8%
In-district placement	61.5	51.9	75.0
Out-of-district placement	38.5	48.1	25.0

at community placement (13 years) would have made such training appropriate.

A second service related to educational programming is training in "activities of daily living," often referred to as self-help skills or self-care skills. This very important educational need was provided to most of the sample. During the first community placement, 63.5 percent of the children participated in ADL training; 75 percent of those who went to a second placement received such training.

Finally, one option for educational services is to provide home-based tutoring. This choice could be highly restrictive in the sense that opportunities for interaction with other children would be non-existent, and the burden on the parents to care for their child during school hours could be significant. Very few children in either first or second community placement received home-based tutoring—7.9 percent of those in the initial placement and 3.6 percent of those who went on to a second placement.

Stability of Educational Placements

As can be seen in Table 7.3, slightly over half (53.8 percent) of children who received any educational services changed placements at least once after their initial assignment. Less than one quarter of the sample (23.1 percent) went to a third educational placement. Table 7.3 indicates the average duration of these placements, the range of duration, and the percentage of placements that lasted less than one year and more than three years. As with residential

Table 7.3

Stability of Educational Placements

Order of Placement	Length of Placement: Average in Years	Range in Years	Percent of Placements<1 Year	Percent of Placements>3 Years
First educational placement (n=52)	2.2	.02-7.0	45.1%	29.4%
Second educational placement (n=28)	2.9	.20-13.0	48.1	40.7
Third educational placement (n=12)	3.8	.50-11.0	33.3	41.7

placements, the average length of stay increased with the number of placements, and a substantial proportion of placements lasted less than one year. However, the frequency of longer placements (those lasting more than three years) increased with the number of placements.

The reasons for changing educational placements varied between the first and second placements and the second and third placements. When children moved into a second educational placement (n=28), they did so for the following reasons, listed in their relative order of frequency:

- Child having a difficult time in the present placement (20%)
- Child too old for the placement (15%)
- Child changed residential placements (12.5%)
- Child transferred to a work or vocational training program (12.5%)
- Child placed in integrated setting (5%)
- Child graduated (5%)
- Family problems required a change in placement (5%)

When children moved from a second to a third educational placement (n=12), the most frequent reasons for the changes were as follows:

- Child changed residential placements (30%)
- Child too old for the placement (25%)
- Parent requested a change in placement (16.7%)
- Child placed in integrated setting (16.7%)

These findings can be compared to the reasons for changes in residential placements, described in Chapter Six. The most

frequently cited reason for initial changes in residential placement was related to the child's inability to adapt to the environment; i.e., his or her behavior was deemed too extreme for the setting. The same thing seems to hold for initial changes in educational placements. On the other hand, parents appear to play a lesser role in changes in educational settings than in residential settings. Although they often were the ones to request a change in residential placements, they had relatively little role in initiating changes in educational placements. In both types of changes, extreme medical needs were a minor or non-existent factor.

Frequency of Formal Disputes

Data were collected on the frequency of due process hearings in the deinstitutionalized sample. Because most of this group of children had not previously received local educational services, and because their needs as a whole were more complex than those of most special education students, it might be expected that the frequency of disputes over educational placement and programming would be higher than normal. This does not appear to be the case. Of the 68 children who were followed, only one experienced a due process hearing. In this one case, the child was initially placed in a public school special education program in the fall of 1981, but no Individual Education Plan was developed. The mother was very dissatisfied with the lack of services, referring to the placement as "babysitting." She sought representation from attorneys at Legal Assistance and the Protection and Advocacy Center, and successfully

argued for placement in a private special education program in the same town. She has been very pleased with the new program, and feels that her son's abilities have improved dramatically since the placement.

The low frequency of due process hearings is consistent with the finding that changes in educational palcements occurred for reasons other than parents' requests. As in other areas of this study, we found that parents of deinstitutionalized children were not aggressive in seeking community services for their children. A fairly low level of expectations about what their children are entitled to or what is available may have acted to hold down the frequency of these kinds of disputes. The fact that over one-fifth of the sample received no educational services, with no ensuing due process complaints or litigation, supports this notion. In some cases, parents were not available to advocate for services, although many children without available parents were assigned a Public Guardian, whose job is to actively pursue appropriate services. An additional factor to bear in mind here is that only 19 members of the sample left LSS after 1978, when due process guarantees were fully implemented under P.L. 94-142. And those children who left most recently under the terms of the federal district court order were followed very closely by Legal Assistance and other advocates to assure appropriate placement and services.

Effect of Time on Educational Placements

As was the case with residential placements, it is possible to detect important differences in the experiences of children who left before and after the implementation of special education policies and the LSS court order. Table 7.4 indicates that children who left LSS in the period from 1970 through 1972 were equally divided between in-district and out-of-district placements. And members of this cohort were much less likely to attend school at all. Of the 23 children who left during this time period, 47.8 percent (n=11) received no educational services. In the 1976-1978 cohort, there are signs of improvement. Only 2 children out of the 14 who left during this period received no educational services. Two-thirds of those who did attend school were placed in local (in-district) programs, and one-third attended out-of-district programs. In the most recent cohort (1982-1985), all children who left LSS (n=12) attended school, with three-quarters placed in local programs and one-quarter in out-of-district programs. These differences across cohorts are statistically significant (p=.021).

Type of educational setting varied somewhat with time, although not at a level that was statistically significant. The strongest trend was in the direction of greater reliance on specialized non-residential schools during the more recent years. Prior to 1979, 62.9 percent (n=22) of those who left LSS and received schooling were placed in such a setting. During and after 1979, 76.5 percent (n=13) of those who left and received an educational program went to a

Table 7.4

The Relation of Historical Periods
to Educational Placement

Location of Educational Program	Percent of Children in Each Program Location During Three Historical Periods*		
	1970-72	1976-78	1982-85
No school assigned	47.8%	14.3%	0 %
In-district placement	50	66.7	75.0
Out-of-district placement	50	33.3	25.0

*p=.021

special non-residential school. This finding should be analyzed in light of the fact that children who left in the more recent period were more severely handicapped than those who left earlier. In general, the type of educational program used for deinstitutionalized children, and the inferred degree of restrictiveness of such programs, showed little change over the 15 year period.

Quality of Educational Services

Although our investigation was unable to assess the quality of educational services received by the members of our sample, AGH Associates (1985) reviewed the level and quality of educational programming received by 20 school-age children who previously lived at LSS. This study was conducted in the spring of 1985, and its results are helpful in casting additional light on the more descriptive findings of the present study.

Of the 20 students included in the AGH sample, 14 (70%) had an Individual Educational Plan (IEP) which described the specific educational program they were to receive. Given that both federal and state laws require such a plan for all handicapped children, the absence of an IEP for a significant proportion of the group indicates some number of deinstitutionalized children are at risk for inadequate or inappropriate services. Of those 14 children who did have an IEP, six of the IEPs were developed just prior to the site visit by the AGH research team.

Between 65 percent and 85 percent of the IEPs had unacceptable or inadequate descriptions of student strengths, weaknesses, present

levels of functioning, and mainstreaming goals, all of which are IEP components required by state and federal regulations. The short-term instructional objectives were generally unmeasurable, vague, and without specified outcome criteria.

In general, the AGH report found that the IEPs were not based on the needs of individual students and did not establish the critical instructional link between the child's needs (based on comprehensive assessments) and individual program goals. In several cases, related serices such as physical therapy and occupational therapy were not being provided although they were identified as needed services. No IEP identified parent counseling as an appropriate related service, although there is much evidence in our study and elsewhere that severely handicapped children create significant problems for their families that could be ameliorated through parent support.

When the reserarch team visited the children's actual classrooms, they observed a lack of age-appropriate and developmentally-appropriate curriculum materials, and frequent reliance on educationally restrictive environments. Only 8 out of 20 students were enrolled in a public school program, a smaller proportion than those in our sample cohort who most recently left LSS. Three students were enrolled in sheltered workshops, and the remaining nine were attending private schools, most of which were residential. Mainstreaming opportunities were minimal for all students, regardless of placement. Only one child enrolled in public school participated in educational or noneducational (lunch, recess, field trips, etc.) activities with nonhandicapped children. None of the children in

workshops or private settings had opportunities to interact with their nonhandicapped peers during the day. The AGH report concluded that the quality of services was superior in the private schools, although this advantage was compromised by the segregated nature of these settings.

The report also assessed the perspectives of school personnel toward the services being received by these deinstitutionalized children. Staff identified problems such as inadequate medical care, overuse of psychotropic medications, inadequate planning for the transition between LSS and the community program, and inadequate training and technical assistance for local teachers who were assigned to this group of children.

The report included two interesting recommendations worthy of mention here. First, the report suggested that a "centralized long term care facility may need to be contemplated as the most viable option" (p. 39) for those children who require extensive care. This seems to be a call for a return to institutional care for severely handicapped children, although there was no evidence to support this recommendation in the findings. There were several major problems uncovered in assessing community-based educational services for these previously institutionalized children, but the problems are remediable through full implementation of state and federal regulations. Reducing opportunities for community integration and for care as close to home as possible would exacerbate the family and child stresses associated with centralized, institutional care, problems which have been extensively documented (see Chapter Eight).

Second, the AGH report claimed that, "There are various valid reasons for students with severe handicaps to receive a program of reduced hours" (p.45). Again, there was no documentation presented in the findings to back up such an assertion. In general, studies have found a direct correlation between the intensity and duration of intervention and educational outcomes, particularly for children with severe impairments. Certainly this group of children is not easy to educate, nor is their education inexpensive. But the various problems cited in the report, such as inadequate IEPs, untrained teachers, and use of segregated settings will not be resolved by reducing the educational effort.

In spite of these flaws, the AGH report is quite helpful in bringing to light the educational experiences of children after they leave a residential institution. Its findings concerning the quality of IEPs and problems encountered in community-based programming add some depth to the broader, more comprehensive focus of the present study.

Summary

The findings in this chapter indicate positive change in the types of educational services and placements received by deinstitutionalized children since 1970. Although over one-fifth of the children received no educational services when they returned to their home communities, the large majority of this group left the State School before legislative mandates for special education became fully developed. The

permissive language that was in effect prior to 1978 at the state and federal level did seem to allow for the exclusion of some children. However, the stringent mandates that took effect in late 1978 were successful in assuring that even the most severely and multiply handicapped children were educated. Positive trends were also discovered in the greater use of local, public school programs rather than distant, private placements, and in the greater availability of support services.

Concerns remain, however, with regard to the availability of prevocational and vocational training and continued reliance on segregated programs that do not provide opportunities for participation with normal groups of children and adults. Children are attending school in public facilities closer to their homes, but this has not led to a significant degree of "mainstreaming" in social or academic domains. In addition, there is evidence that the quality of special education programs is less than adequate when measured against the regulatory criteria in state and federal laws. These issues will be discussed more fully in the analysis section in Chapter Nine.

Chapter Eight

The Effects of Community Placement on Families

In this chapter, the many issues that parents face in seeking admission of their children to Laconia State School and Training Center, in dealing with institutional residence, and in confronting the deinstitutionalization process and community placement will be discussed. It is the purpose here to not only describe response patterns but to bring to light parents' concerns as they arose. It is important to keep in mind the historical context of these concerns.

Although parents have always fought for improved services for their handicapped children, they did not take the lead in calling for the deinstitutionalization process that began in the 1960s. Often parents have argued for more effective and humane institutional care. The strong push for almost exclusive reliance on community-based care has come from professional advocates, policy-makers, academics, and civil rights attorneys. These advocates have been stimulated and supported by small numbers of vocal, assertive, politically savvy parents of severely handicapped children. But in general, parents have resisted community placement out of concern that their children would be made to live in unsafe, inadequate facilities where lack of supervision and exploitation would be more likely to occur than in a closed institution. Parents have also been fearful that they might be required to assume legal, financial, and psychological responsibility for their children. In light of the pain and grief associated with the early stages of diagnosis and institutional placement, and the

many intervening years when families adjusted to living without their severely handicapped child, the possibility of involuntary reintegration of the child into the family is viewed with great trepidation. As we shall see in the later discussion, the move to place children out of LSS was not initiated or supported by most parents whose children lived there. However, we shall also see the the drastic changes that occurred from 1970 to 1985 caused significant changes in parents' attitudes toward community care.

Initial Placement Decisions

The median admission year to LSS was 1970 for Population One and 1965 for Population Two. Even at these late dates, alternative residential and educational programs were not available in most regions of the state. Placement in the institution is usually a difficult decision fraught with guilt and feelings of helplessness and frustration. However, a subtle distinction emerges between the two populations regarding this decision process. Population One parents tended to encounter barriers to their child's admission which they had to overcome, whereas Population Two parents were more often encouraged at the outset to institutionalize their disabled offspring. For the second group, this impetus tended to come only from professionals, but Population One parents tended to receive advice to place their children from professionals, other family members and neighbors. This supports the earlier observation that Population Two families were somewhat higher in socioeconomic status, which correlates with a greater reliance upon professional input. As

well, Population Two children were more severely handicapped, leading to more frequent contact with a variety of professionals and greater likelihood of consensus concerning the decision to institutionalize.

Seventy-nine percent of all the participating parents were the ones who first initiated admission of their children to LSS; 76.5% of Population One parents first applied for their child's admission and 80.7% of Population Two parents began the process. Though these two groups each had difficulties with the admission process, there were some distinctive qualitative differences that were revealed in in-depth interviews.

Though both groups spoke of the mother's coping resources being depleted and the significant behavior problems presented by their children, it appears that Population One parents were more likely to use these reasons to press for admission. One mother threatened, "If you don't take him, you'll have to admit me to New Hampshire Hospital!" A father reported, "It took nine years to get Carl into LSS for a four day per week, four month program [for toileting and self-care]." Carl had been on the waiting list since one year of age but didn't get in until his father complained to the central office in the State capital, asserting that his wife was "on the verge of a breakdown."

At times the situation became desperate. A mother told us her foster child was abandoned as an infant at LSS by the child's father who, at the time, had become a widower. The father sought admission for an evaluation and never returned to reclaim his child.

Population Two parents seemed to experience pressure early on to institutionalize their children. On the whole, their children were placed at LSS at a slightly younger age and at an earlier point in history, when community placement was barely contemplated in the public mind. Doctors were more adamant about institutionalizing mentally retarded children. "Better put him away. He's an idiot," admonished one physician. In another painful recollection, a mother was told by the family doctor, "Get her out of the house as fast as you can. What is the use of cutting off the puppy dog's tail by inches?" But even physicians manifested difficulty in advising parents. A mother told us, "At first the doctor said take him home and love him; later he said, 'Put him in the State School'."

Since Population One children tended to be somewhat more active than their Population Two counterparts and entered LSS at a somewhat later age and at a later point in history, parents reported that they were subject to social pressures of relatives, teachers, their children's schoolmates and neighbors. One parent said pressure from teachers and the teasing of schoolmates made keeping her child at home increasingly difficult. In another instance, parents were told by the school district that LSS was the "only" place their daughter could be evaluated in order to be accepted for any program in the state. Another mother explained the painful shunning of her neighbors. "The townspeople were hateful to her...they wanted to get rid of her--Vicky was an undesirable in town."

Another child, Dennis, was not learning in school, having seizures and being teased by other students. Family members blamed Dennis' mother for his seizures and his problematic behavior, saying she spoiled him when she should have disciplined him. Finally, a woman in her husband's office whose child was at LSS suggested to Dennis' father that Dennis might benefit from placement there.

Other family members also encouraged parents to admit their disabled relatives. A Population One mother whose husband and father-in-law were both ex-residents of LSS reported that a cousin had urged her to place her daughter.

A Population Two mother explained, "We polled extended family members to see what they thought. When my father's aunt and her husband had agreed to keep all the kids <u>except</u> Gerard in case of [our] death--<u>that</u> was the deciding factor!"

At a point in history when there were two choices, home or the institution, parents experienced great frustration. When one mother could no longer handle her daughter at home because of her terrible behavior and because there were no other possibilities, the family placed the child at LSS. The frustration, however, of witnessing her child's rapid regression forced the mother to quickly take her home. "I had to toilet train her all over again!" she told us.

One of the most powerful and revealing experiences in the study came when a mother denied consent for her daughter to be included. In withholding consent, the mother wrote on the consent form, "Under no circumstances can anyone use Diane as a case study for any purpose whatsoever. If you want to know why, call me." We did. In an

intense, one-sided telephone call that ran close to an hour, Diane's mother explained, in poignant terms, her emotional state at the time of admission to LSS and the years that followed.

Diane's mother told us her daughter's severe impairments were evident soon after birth. She sought a diagnosis and treatment for the next seven years. She eventually received a diagnosis at a private agency in New Hampshire, but was told there was nothing that could be done for her (this occurred in the late 1960s). When she was nine years old, Diane was placed at LSS by her parents on the advice of the family physician and staff at a private diagnostic agency. The mother felt defeated in her efforts to care for Diane at home but also wanted some relief from the burdens she faced. She told us, "I washed diapers for 30 of the 35 years I was married. I just couldn't keep on like that."

The period of institutional placement created an even greater emotional burden. The body brace Diane wore to correct her scoliosis disappeared soon after institutionalization. Visits became extremely difficult.

> Her father and I would cry for days after being there [LSS]. There were some days I wished I'd never wake up because of what I'd seen there. They tied people down on all fours. The staff takes advantage of the girls there. It's worse than a kennel. Any perfectly sane person would go insane. When we went there, we felt like they [the staff] would just as soon not have us around.

Diane left the State School when she was 13 years old, and has lived in two different nursing homes since then. Her mother believed (as did some others who denied consent) that involvement in this

study would result in Diane's return to the school. This mother's intense guilt and anger over past events and fear for her daughter's future may have been expressed more vehemently than the emotions felt by those parents who gave consent, but the nature of her comments is consistent with the feelings and experiences of other parents. It is clear that the initial admission decision and the subsequent period of residency were times of regret and grief. For neither population was the decision to seek their children's admission to LSS an easy one and once their children were there, it was not always easy to visit.

Visitation Patterns

Visitors to Laconia State School are required to report to the administration building before going to the units and cottages to visit residents. The visits are recorded at the time and kept in a file separate from the residents' medical and behavioral records. Since visitors are not always consistently identified, no distinction was made--in recording data--as to whether the visitors were kin or others, though for the most part, they were relatives, according to the reports of staff and parents. In some instances, a resident was visited by LSS staff or community staff preparing the resident for placement.

As can be seen from Table 8.1, Population Two residents clearly were not visited as often as Population One residents. Though a small percentage of people were never visited during their stay at

Table 8.1

Total and Average Number of Visits Per Year by Population in Comparison with Length of Stay at LSS

	Population		
	One	Two	Total
	n=67	n=102	n=169
Total number of visits during stay at LSS			
Median	18	12	14
Mean	37.0*	25.8*	30.3
SD	53.0	35.4	43.6
Average yearly visits	4.2*	.9*	1.5
Average length of stay at LSS (years)	5.4*	13.7*	9.3

*p<.05

LSS, in any given year (from 1970 to 1983), about one-third of the total population did not receive visitors. Again, this varied somewhat by population. On average, in any given year, 36% of Population Two was not visited; 31% of Population One was not visited. (The year 1984 was not counted in this analysis because it was the only year when all remaining Population One residents received no visitors and so represented an extreme value.)

From Table 8.1, it can be deduced that the longer the stay at LSS, the fewer the visits. This is not a new finding. It is one of the unfortunate correlates that make institutions so insular. Another is distance. It was not uncommon for a parent to tell us, "We'd visit more if it didn't take two hours to get there." Or, "It's not that I don't want to visit Larry, it's just that it's so depressing to see the other residents." A mother of a very severely involved child, who required 24-hour physical attention told us the sight of her son was too painful to her. These parents did not gain the sympathy of LSS staff who shared openly their disparaging remarks with us. When a parent broke through his/her inertia to make a visit, the staff, who were keeping score, often conveyed their scorn, making subsequent visits even more difficult and unlikely.

Informal and Formal Mechanisms of Coping

In order to obtain a picture of the human resources available to the parents in our study, we asked them several questions about the sources of assistance they could draw upon over the years. Each

parent was read a list of possible resource groups and asked to tell us how frequently each gave assistance. The list included family, friends, neighbors, co-workers, other parents, clergy, doctors and "other." In addition, parents were asked to tell us who in this list was the most supportive, and to rate the level of supportiveness of extended kin.

The responses overwhelmingly pointed to the family as the greatest resource. Forty-nine percent of Population One parents said they received daily assistance from their families and another 8.5% received at least weekly assistance in the form of babysitting, chauffering or advice by telephone. Thirty-nine percent of Population Two parents reported daily help and another 17.5% reported help from their families on a monthly basis. While Population One parents said their immediate families were most helpful, Population Two parents said they received the most support from extended kin.

Population Two parents said their extended kin were extremely supportive (54.2%); an additional 20.8% said kin were somewhat supportive. Of Population One, 40.4% reported their kin were extremely supportive; another 8.8% chose "somewhat supportive" to describe kin involvement; but 31.6% said kin were not supportive or made things worse.

Of non-kin, friends and neighbors and then other parents were the most frequently available resources. Parents reported that friends supplied daily and weekly support, whereas neighbors were somewhat less available (or less relied upon). Some of the parents had found moral support and information from other parents of

developmentally disabled children (e.g., in monthly gatherings at their children's school or at meetings of the local Association for Retarded Citizens.)

Though, for the most part, Population Two parents had little or no contact with regional service providers, Population One parents indicated that local staff in their county hospital or private center for services for developmentally disabled people provided assistance.

Parents' Attitudes Toward Deinstitutionalization

The two main methods of data collection which inform this discussion are the Attitudes Toward Deinstitutionalization Scale (ATDS) developed by James Conroy and his colleagues for the Pennhurst Study (Conroy, 1985) and in-depth interviews conducted in the period between 1984 and 1985. In addition, anecdotal data made available from a survey conducted by two parents will be presented to shed light on issues revolving around opposition to deinstitutionalization.

Table 8.2 shows the percentage breakdown of informants. Mothers comprised the largest portion of informants about family attitudes and reactions to deinstitutionalization. Though in twenty percent of the interviews, both mothers and fathers were present, just the responses of the mothers were coded, since they acted as key informants for the most part.

Table 8.2

Parent Interview Informants

	Population 1		Population 2	
	n	%	n	%
Father	7	10.8	2	8.0
Mother	33	50.8	16	64.0
Both Parents	13	20.0	7	28.0
Foster Mother	3	4.6		
Foster Father	1	1.4		
Both Foster Parents	1	1.5		
Other (relative, guardian)	7	10.8		
Total	65		25	

ATDS Results

The ATDS was divided into two parts for purposes of discussion and analysis. The first part is the Impact Scale which consists of items having to do with how parents perceive changes in their family life activities as a result of or as an anticipated result of their child's placement into the community. The second part of the ATDS addresses the ideological issues of deinstitutionalization.

ATDS: Impact Scale. The Impact Scale consists of a list of fourteen routine family activities. The parent is asked to judge to what extent these activities change as the result of his or her child being placed in the community. Population One parents answered in retrospect and Population Two parents were asked to respond according to how they anticipated their lives might change as a result of their children returning to the community.

On a scale of one (change for the worse) to five (change for the better) the parent assessed the impact of the child's return on the following items: his or her own social life, job, spouse's job, family home recreation, time alone, time with spouse and with the other children still at home, family vacations, own general happiness, the parent's assessment of the developmentally disabled child's happiness, and the child's relationship with the respondent, the spouse, with siblings and with others.

Table 8.3 displays the means and standard deviations for each item in the Impact Scale for each population.

Though, overall, the median response was 3, i.e., no change, with regard to family activities, some concerns were detected. Both

Table 8.3

Parents' Assessment of the Impact Upon Family Life of Their Child's Return to the Community

	Population 1 (n=63)		Population 2 (n=25)	
Area of Impact	Mean (a)	S.D.	Mean	S.D.
Your own social life	2.9	1.2	3.1	.5
Your job	3.0	.7	2.9	.4
Your spouse's job	3.1	.5	3.0	.6
Family home recreation	2.9	.9	3.1	.9
Your time alone	2.9	1.2	2.8	.7
Your time with spouse	2.9	1.0	3.0	.6
Time with other children	3.0	.9	2.9	.4
Family vacations	3.0	1.1	3.0	.2
Your own general happiness	3.9	1.2	3.2	1.5
Your child's happiness	4.3*	.9	3.1*	1.5
Child's relation with you	3.7	1.1	3.5	1.0
Child's relation with your spouse	3.6	.9	3.4	1.4
Child's relation with siblings	3.5	1.0	3.4	.5
Child's relation with others	4.1+	1.0	3.5+	1.2

*p<.001 +p<.03

(a) Higher values indicate more positive impact

groups of mothers thought their children's placement might impinge upon their time alone. While Population One mothers showed some concern for their social life, family recreation and their time with their spouse, Population Two mothers were concerned that placement would interfere with their time spent with their other children. However, unlike Population One mothers, Population Two mothers gave a small indication that family recreation at home might improve as a result of their child's community placement.

With regard to emotional issues and social relationships, parents showed positive feelings toward community placement. Mothers in both populations perceived or anticipated a change for the better with regard to their children's relationship to others as well as to family members. Population One mothers saw their children as much happier now than they were in the community. Mothers told us that since they saw their children were happier, they were happier as well.

Cohort Differences. Parents whose children left LSS after 1978 were statistically more likely to say their own general happiness had changed for the better (Chi-sq=11.263,<03;df=4) and that their handicapped child's relationship with them had improved as a result of leaving the institution (Chi-sq=10.051,<.05;df=4) (See Tables 8.4 and 8.5).

ATDS: Deinstitutionalization Ideology.

The second part of the ATDS consists of eleven ideological statements concerning deinstitutionalization as applied to the informant's

Table 8.4

Cohort Differences of Impact of Community Placement on Parents' General Happiness*

	Placement in or before 1978 (n=44)	Placement after 1978 (n=18)	Total
Change for the worse	3 (6.8%)	0 (.0)	3 (4.8%)
	4 (9.1%)	1 (5.6%)	5 (8.1%)
No change	15 (34.1%)	2 (11.1%)	17 (27.4%)
	8 (18.2%)	1 (5.6%)	9 (14.5%)
Change for the better	14 (31.8%)	14 (77.8%)	28 (45.2%)

*Chi-sq=11.263<.03; df=4

Table 8.5

Cohort Differences of the Impact of Community Placement on Child's Relationship with Mother*

	Placement in or before 1978 (n=45)	Placement after 1978 (n=17)	Total
Change for the worse	0 .0	1 (5.9%)	1 (1.6%)
	6 (13.3%)	0 (.0)	6 (9.7%)
No change	18 (40.0%)	8 (47.1%)	26 (41.9%)
	9 (20.0%)	0 (.0)	9 (14.5%)
Change for the better	12 (26.7%)	8 (47.1%)	20 (32.3%)

*Chi-sq=10.051<.05; df=4

developmentally disabled child. The parent was asked to respond to each statement with "strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, and strongly disagree." Table 8.6 shows the mean scores for both groups for each item. Note that the higher the score, the more the group agrees with the principles of normalization. Thus, strongly disagreeing with the statement that the child has reached his/her developmental limit or with the statement that the child should live in the same home for a lifetime, is coded 5 while strongly agreeing is coded 1.

Table 8.6 shows the items contained in the second part of the ATDS. For the most part, Population One parents are highly accepting of deinstitutionalization ideology. Each item will now be discussed in turn.

Developmental Model. For the first statement, "I believe my relative has reached his/her highest level of educational and psychological development and will not progress much beyond the level she/he is at now," the mean score was 3.8 for Population One and 3.2 for Population Two. Optimism that their children could still progress was not significantly influenced by the child's diagnosis. Further analysis revealed that parents of severely retarded children strongly disagreed with this statement in 63.6% of the cases, and 50% of parents of profoundly retarded children also did not believe their children had reached their full potential.

These findings are in sharp contrast to those of Conroy (1985). The Pennhurst families agreed with the statement, i.e., that the

Table 8.6

Parents' Attitudes Toward Deinstitutionalization

	Population 1 (n=63)		Population 2 (n=25)	
	Mean	S.D.	Mean	S.D.
1. Child has reached developmental limits	3.8	1.5	3.2	1.2
2. Same residence for life	3.1*	1.5	2.3*	1.6
3. Open setting to match skills	3.8*	1.3	3.2*	1.6
4. Community workers competent	3.5*	1.3	2.8*	1.3
5. Community funds are secure	2.1	1.2	2.0	1.3
6. Needed services are available	3.1	1.5	2.6	1.6
7. Financial burdens lifted	3.4	1.5	3.4	1.2
8. Normalization	4.7*	.6	3.6*	1.4
9. Least restrictive alternative	4.8*	.5	4.0*	1.3
10. Deinstitutionalization	4.7*	.9	3.1*	1.9
11. Discharge decision	4.5*	1.2	2.9*	1.6

*p<.05

The items in the table refer to the following questions to which the respondent answers "strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree.

1. I believe that my relative has reached his/her educational and psychological development and will <u>not</u> progress much beyond the level he/she is at now.

2. When my relative lives away from home, I prefer that he/she remain in the same place his/her entire lifetime.

3. When my relative lives away from home, I prefer that he/she move from a more protected residential setting to a more open setting as she/he achieves greater self-help skills.

Table 8.6 (continued)

4. Persons who work in community living arrangements are knowledgeable and skillful enough to handle situations which may arise with regard to my developmentally disabled relative.

5. I believe that funding for community arrangements is secure and permanent.

6. I believe that all services needed by my developmentally disabled relative are available to him/her in the community.

7. I believe that my family has not had to assume added financial burdens for the care of my relative since he/she has been (or will be) living in the community.

8. Normalization means that, as much as possible, developmentally disabled persons are given normal opportunities for living, working, and school. In thinking about what your relative will need in the future, how much do you agree with this concept?

9. The Least Restrictive Alternative says that developmentally disabled persons should be allowed to live in places which are as much like normal homes as possible. In thinking about what your relative will need in the future, how much do you agree with this concept?

10. Deinstitutionalization is the moving of developmentally disabled persons from the institution into places in the community. In thinking about what your relative will need in the future, how much do you agree with this concept?

11. When your relative was (is) selected for movement from LSS to the community, how agreeable were you (will you be) to this decision?

children had reached their limit. The author concluded that the families in their sample were not responsive to the developmental model which stresses the notion that all people can grow and learn.

Assuming that the results are true, there are two possible explanations for the discrepancy in our findings. It could be that since our respondents are the parents of a younger cohort than the parents of the Pennhurst population (we limited our sample to residents born in or after 1949 and the Pennhurst study included all residents), they were still hopeful for their children's development and education. The other reason could be that history has had an impact and our parents have had more exposure and therefore more opportunities to adopt a developmental perspective.

Least Restrictive Alternative. Three statements were posed pertaining to the concept of the least restrictive alternative. First, parents were asked if they would prefer their children live in the same home for their entire lifetime. A score of 5 indicated strong disagreement and 1 strong agreement. The mean scores for Populations One and Two were 3.1 and 2.3, respectively.

In our in-depth interviews--especially with Population Two parents--there was a concern expressed for the need for a stable environment which promotes familiarity and good orientation to surroundings so that their children can develop and improve in functioning. Since Population Two parents scored low on this item, our interpretation here is that we can expect greater concern on the part of the parent for stable long-term placement, the greater

the child's impairment and the longer the period of institutional residency.

To the third statement: "When my relative lives away from home, I prefer that she/he move from a more protected residential setting to a more open setting as she/he achieves greater self-help skills," parents responded with greater agreement (3.8 and 3.2).

We asked parents to what extent they favored the concept of the least restrictive alternative as it would apply to their children. Over 90% of all Population One parents and 79.2% of Population Two parents, regardless of their child's diagnosis, supported the concept, yielding means of 4.8 and 4.0, respectively.

Though both groups were in favor of placement in the least restrictive environment, interpretation of this concept demands careful scrutiny. While parents of younger, somewhat less disabled children may interpret it to mean living in a small group home in the city, parents of more disabled persons tend to have a different view. One Population Two mother explained:

> When they took the fences down [at LSS], my heart sank. It meant that James and his friends were not as free to roam. The staff kept them closer to their building. You know, sometimes, fences <u>are</u> the least restrictive alternative! They took the fences down for the sake of <u>appearances</u>, not for the sake of the residents.

<u>Normalization, Deinstitutionalization and the Decision to leave LSS</u>. Referring again to Table 8.6, the two populations differ greatly with regard to these concepts and this decision. While Population One parents are vigorously in favor of normalization,

deinstitutionalization and the decision to discharge their children into the community ($\bar{X}$=4.7, 4.7 and 4.5, respectively), Population Two parents were relatively cautious. Though they ratified the concept of normalization ($\bar{X}$=3.6), as a group they were ambivalent toward the of deinstitutionalization ($\bar{X}$=3.1, S.D.=1.9) and did not favor a decision to discharge their children ($\bar{X}$=2.9, S.D.=1.6).

In order to understand why Population Two parents were split with regard to deinstitutionalization (50% were in favor and 49% opposed), the data were further analyzed to reveal some underlying factors.

First, it was hypothesized that the more severe the child's retardation, the less optimism there would be toward community placement. Jack Melton, the former superintendent of the Laconia State School, noted that in his experience, parents' attitudes correlated with their children's diagnoses. Our data bear this statement out. There is a relative decrease in optimism regarding community placement as the severity of retardation increases.

If the child was already in the community, Population Two parents found it easier to accept the concept of deinstitutionalization. These parents told us that though they were initially opposed to to community placement, now that they had seen it happen for their adult children, they slowly began to see its benefits. Our findings duplicate those of Rudie and Reidl (1984); though parents initially resist the idea of community placement, once placed, they are likely to be satisfied. As one father put it, "I'll believe it when I see it."

Community Services: Competence and Finances. Four statements of the ATDS addressed issues directly related to community services. Table 8.7 shows the mean scores for each group of parents.

Regarding the statement, "I believe that my family has not had to assume added financial burdens for the care of my relative since she/he has been living in the community [or when she/he lives in the community]," most parents were in agreement. Their perception is consistent with the findings in Chapter Six indicating that parents paid for very few community services. There were some instances, however, which suggested that where families were quite involved with their children who were now living in the community, they also shouldered more of the financial responsibility (see the case histories of GG and Cheryl).

Competence. "Persons who work in community living arrangements are knowledgeable and skillful enough to handle situations which arise with regard to your developmentally disabled relative." This statement divided along group lines. While Population One parents were fairly optimistic, Population Two parents remained skeptical. These parents, who in 95% of the cases (n=25) believed their children required 24-hour per day supervision, were concerned that community workers did not have the skills or experience to match those of workers at Laconia State School.

Though confidence was expressed by Population One parents, it was not without reservations. One mother commented:

> People who advise have little or no experience. New teachers - they have lots of theory but no common sense! Most teachers have had no experience with mental retardation.

Table 8.7

Attitudes Toward Community Services

	Population 1		Population 2	
	Mean	S.D.	Mean	S.D.
Financial burdens lifted	3.4	1.5	3.4	1.2
Community workers competent	3.5*	1.3	2.8*	1.3
Funding is secure	2.1	1.2	2.0	1.3
Needed services are available in the community	3.1	1.5	2.6	1.6

*p<.01

Population One parents also showed differences by cohort. Parents of children placed after 1978 were more confident in community workers than the pre-1978 cohort. Parents, especially those of more severely involved children, are not overly anxious to send their children into the community. Parents' skepticism is based on reality--a reality that is corroborated by service providers themselves who admit that they are not adequately trained to handle "surprise" situations, i.e., unpredictable behavior problems.

Funding. Another factor contributing to parents' reservations about community placement has to do with the financing of group homes. We asked parents whether they believed funding for community living arrangements was secure and permanent. About 68% of Population One parents strongly or somewhat disagreed with this statement and about 73% of Population Two parents disagreed.

Availability of Services. Related to the previous finding is the issue of the availability of services in the community. We asked parents to respond to the statement, "I believe that all services needed by my relative are available to him or her in the community." Here we are addressing the contrasting belief that only the institution can provide the necessary services. As expected, Population Two parents still believe there are services the community cannot provide. However, Population One parents are also somewhat skeptical.

Parents of the pre-1978 placement cohort were only 42.8% in agreement with this statement, while the post-1978 cohort was 77.8% in agreement.

This suggests that once again historical context plays an important role in shaping opinion. A father and mother who made the decision to take their son out of LSS, because of "terrible care and overmedication," felt, "Deinstitutionalization is going too fast. Services in the community are not enough to support the clients coming out." They, too, expressed the fear that funding will remain too low and then not be there to support community integration.

Parental Opposition to Deinstitutionalization

In the face of the impending lawsuit against LSS, a husband and wife who were opposed to the closing of the institution sent out a questionnaire in 1979 to approximately 500 families whose relatives were at LSS. Their motivation was the concern that the lawsuit was only representing a vocal minority of parents who wanted to close the school. Thus, they were determined to poll as many parents as they could. When Deborah Watson consented to participate in our study, she came forward with all the returned questionnaires she had received in late 1979 and early 1980. The text of the Watson questionnaire appears in Figure 8.1.

The questionnaire invited comments from those surveyed and thereby provided a forum for parents to express not only their reasons for opposition or support of deinstitutionalization but

for other comments, complaints and expressions of frustration and bewilderment. Parents who believed their children required continued institutional care for medical and behavioral reasons constituted a large majority of the respondents. They wrote that their children were severely retarded and would not benefit from being in the community and would most likely suffer abuse. Other parents were opposed to community placement because of the disruption in their's and their children's lives. LSS was viewed as "home." Often, the problem of the burden of the handicapped child returning to aging parents was raised.

These responses are valuable data contributing to our further understanding of parental objections to deinstitutionalization as a blanket policy. Below are samples of the responses that are part of the New Hampshire version of a scenario that has been played out in its many forms throughout the United States. The parents' comments present one perspective on the situation faced by those with children residing at LSS in the late 1970s.

Mrs. Bridges' comments focus the effect of both the child's level of disability and the parents' circumstances in relation to community placement.

> Each person's response to this 'questionnaire' I feel quite sure will be colored by his (her) own situation as it regards the retarded member of their family: 1. to the degree of brain damage and severity of retardation; 2. the length of time the resident has been institutionalized...; 3. to the age of the parents and the siblings of the Laconia resident; and 4. the stage and circumstances of life the rest of the family happens to be in.

Figure 8.1

The Watson Questionnaire

November 1979

Dear Parent or Guardian,

A class action suit has been filed in U.S. Federal Court on your behalf by six parents and the N.H. Association for Retarded Citizens. This lawsuit could result in community placement of all residents at Laconia State School and lead to the closing of this school.

Do you feel this suit in truth represents your feelings?

Your opinion can have an important bearing on the outcome of this case. Please take this opportunity to state <u>your</u> case. Record your preference below and return this letter immediately to

_____

_____

_____

An envelope is enclosed for your convenience.

Sincerely concerned parents,

Deborah and Lloyd Watson

_____, I favor keeping Laconia State School <u>open</u> with the continued upgrading of facilities and care, and community placement of residents where appropriate.

O
R

_____, I favor community placement, i.e., parental home, group home, or apartment, for <u>every</u> resident of Laconia State School.

Signed _____

Comments:

> I am in favor of continuing the School and in line with above paragraph hope this will be the final determination as: 1. our resident is severely brain damaged though physically almost normal; 2. has been institutionalized since before she was three years old (she is now twenty-two); 3. and 4. the parents are in their late fifties having had four children late in the mother's childbearing years and are now putting two [children] through colleges and a third, the youngest child, will go to college next fall. The father could not adjust ever to an abnormal child in the household as he is even now devastated by the tragedy of a retarded daughter and still cannot even talk about it without emotional strain.
>
> I sincerely believe that for much less severely retarded persons, a more 'everyday' life in the community is more beneficial for them if there are excellent services in communities for special education, job training, etc. and support group for young parents--all parents for that matter.

Parents expressed concern that their children were being uprooted and their children's friendships and social bonds with caring staff and volunteer grandparents were being ignored. Mrs. Boulanger wrote:

> We have visited several times a year, taken her out on trips and she has always been very happy to return to her brothers and sisters at Laconia. It would be a grave injustice to tear up her home and separate her from her loved ones. She is of age, ask her.

Parents also feared the community. Mrs. Gerard wrote:

> Years ago I used to have to work and had to board [my son] out. It didn't work out. People were afraid their normal small children would copy his ways, or think he was normal and fight or hit him and they did!

Aged parents feared a responsibility they could not manage. Mrs. Allen wrote:

> It would be wonderful if all of the residents could leave the School...We were told our poor little daughter would not reach her third birthday. She is twenty-three. It would be impossible for me to care for her. I am sixty-three and in poor health.

Mrs. Lombard stated:

> I am a widow living on social security. I have a bad case of arthritis and have problems getting around. So healthwise and financially I couldn't possibly take care of my retarded daughter. In my opinion she has been taken care of very well [at LSS].

Some relatives wrote the Watsons, explaining how they wanted and were actively seeking alternatives to LSS. A letter from a resident's sister read:

> ...[M]y sister is crippled...she is either in bed or in a chair all the time; I have given this very serious thought and being her guardian, I feel it is best for her to be moved back to Colebrook, NH. We have a very good nursing home. She would be near her folks, and I am going to make all preparations for her to be brought home. Then if Laconia State School is closed I won't have that worry on my mind.

Others had decided to wait and see.

> We would be very happy to have C. near us in the community, <u>but</u> we feel there is no proper place yet around her for care of this kind. When the planning and arrangements evolve to where they have such places, we'll be the first to ask for it.
>
> Perhaps in a few years, it will happen, we hope so. Thank you.

From our interviews conducted six years after the Watson survey, we uncovered similiar concerns regarding deinstitutionalization. In the following sections are excerpts from comments made during the interviews. Our interviewers were instructed to invite parents to freely make comments throughout the interview and to raise issues and concerns that may not have been addressed by our questions.

Fear of the Community. One mother told us she was opposed to deinstitutionalization because:

> I'm afraid of what can happen to him outside--what's around him--not him. In the community he can't move independently. At LSS he moves around independently. I have a fear of George not being taken care of if something happens to us. That's why we put him at LSS. LSS is his home and he's being uprooted.

Parents sometimes view the suggestion of foster placement almost as an indictment. "If I can't do it, I don't see how they can do it." But in the same breath, this mother revealed her ambivalence, "I was hoping he'd get into [a group home] but he hasn't yet."

A father expressed additional concerns about community placement with regard to the social reaction to his son in the community.

> Most people don't know how to cope with the situations--to confront them on the street, in a store. 'Look at this retard.' 'Why do we have that type in the community?' You hear all kinds of comments and they're all negative... If he were moving to [the next town over] or a little closer to home, I'd be for it but if it were another community I'm not sure--if it were

> a community used to retarded kids...Not unless they prove to me that he's capable of handling the situation.... I think they're pushing these kids into the community too fast. Of course, I realize that some need to be in the community to develop their limited skills, but, I don't think they should push them out of LSS to make room for others to go to the institution. I think they're trying to eliminate a service.

A mother described her view that some community living arrangements lacked the stability of the institution.

> There is a certain permanency in an institution that there will not be in a foster home. The personnel may change but the physical plant would not change as a foster home might after a certain number of years. The building, the house, might come up for sale; the foster parents could not go on forever. (Neither would the staff at the school be there always, I'm aware.) However, the institution for the most severely retarded should remain stable--not up for land grabs or sold. There is less of a chance for disruption [of care] in a school than in a home, in my opinion, for a badly brain-damaged person.

Social Growth as a Result of Deinstitutionalization. Parents were asked to note changes in their child's abilities and to give their opinions as to the reasons for these changes (either positive or negative). Where parents noted improvements in the level of their child's functioning, most often they attributed the change to programming that specifically addressed a particular problem. This was true for self-care skills, hearing, vision and speech. However, they also regarded the "normal home environment," the "exposure to people and social activities," maturation and a "secure and loving home" as positive influences. "Nancy has grown more since her living in the group home than she ever did in 20 years--[she] has grown most in the past year."

Another parent reported:

> Because of the program at the Moore Center, he has learned more in the past two years than in all other years of his life. [Donald] is more at ease...has calmed down to appreciate other people and things... The program my son is receiving is fabulous. I could not ask for anything better. He has learned so much in the past two years.

One couple described their delight with their daughter's progress in the community. They told us that in the Christmases of 1982 and 1983, Margery did her own shopping (with group home staff) for her parents and was very proud and happy and involved with the Christmas spirit for the first time. Margery's integrated home economics class put on a dinner at a corporation. Each student had to say their name afterward; Margery did this along with "normal" peers and her parents were "so surprised." Her parents have Margery for dinner once a week and home for Christmas and her birthday.

Summary

Parents in our study have lived through sweeping historical changes in the treatment of their children. From a time when professionals urged institutionalization to the present impetus toward communitization, these parents have, for the most part, adjusted.

The two populations differed on a number of key points.

1. Population One parents had to fight to place their children at LSS, whereas Population Two parents were urged to place their children there. This was due to the fact that Population Two children were, on average, more severely retarded and placed at LSS before the deinstitutionalization movement began.

2. Population Two children were visited significantly less often than Population One children.

3. In looking at the informal and formal support networks outside the institution, we saw that the greatest and most frequent support came from the families themselves. Population One families received more frequent help from their families than did Population Two.

4. Regarding attitudes toward deinstitutionalization and its impact, in general, mothers reported that community placement is, or in the case of Population Two, would be a positive change, especially with regard to their children's relationship with all members of the family and with others. Population One mothers saw their children's happiness as greatly improved. Population Two mothers tended not to be able to anticipate this outcome. Parents whose children left LSS after 1978 were more enthusiastic about their children's placement than parents whose children were placed before 1978.

With regard to normalization ideology, we found that both groups supported the concepts of the developmental model, normalization and the least restrictive alternative. But with regard to deinstitutionalization, the two groups diverged, with Population

One strongly in support and Population Two somewhat opposed. However, of the Population Two parents whose children were actually now placed in the community, five out of six were in favor of deinstitutionalization.

The two groups of parents were identical in their view that funding for community facilities is neither secure nor permanent. However, Population One parents did believe that the services their children needed were available in the community. Population Two parents were less confident in community services and personnel.

5. In examining the main issues regarding opposition to deinstitutionalization, the results from a survey conducted in 1979 by two parents whose child was at LSS at the time and the comments from the interviews we conducted in 1984 and 1985 revealed that many of the same concerns about deinstitutionalization are still contributing to parental resistance.

Parents are still concerned that the closing of LSS and unsuccessful community placement may leave them burdened with the financial, physical and emotional care of their disabled children. Aged parents still assume that there are only two alternatives: home or institution. Not being able to care for their children, parents fear their children will not have a secure and safe place to live (after the parents are dead) if their children leave the institution. Other parents were concerned about the lack of community acceptance of their children. However, parents whose children have had successful placements in good programs in the community have described their satisfaction in seeing their children improve in skills, social development, and personal happiness.

Chapter Nine

Summary and Analysis of the Findings

In light of the findings presented in the preceding chapters, it is possible to answer the questions posed in Chapter One. Before doing so, it is necessary to reiterate the limitations of this particular study. Our results are based on a sample of about 45 percent of those children who left one public residential institution for mentally retarded people between 1970 and 1985. The experiences of those children occurred in a small, primarily rural state with a service delivery system that was developed only during the later years of this time period. A unique public financing system that relies heavily on local taxes and very little on state or federal funds has created the economic context for the deinstitutionalization process in this particular state.

On the other hand, there have been some important similarities in the experiences of these children compared with those of children in other states. The historical patterns of institutional care and subsequent deinstitutionalization have almost directly mirrored patterns elsewhere. The history of policy making, litigation, and service development in New Hampshire have also reflected patterns in most other states. If anything, the relative lateness of program development in New Hampshire has led to a more rapid implementation of community based services and a greater fiscal commitment on the part of the state than has been the case in other areas. The changes have been dramatic and not solely due to the pressure of litigation. A small but influential group of parents of children living at the State School, effective professional advocates, and progressive

administrators and policy makers coalesced in the 1970s to create the changes that this report documents. It is, therefore, not possible to make sweeping generalizations from our data to experiences in other states. But in situations with historical, economic, and social circumstances similar to those in New Hampshire, there are clearly lessons to be drawn.

This report began with an historical overview of institutional and community based care in the United States and New Hampshire specifically. After a century or more of reliance on institutional care, first for the benefit of the individual and later for the benefit of society, a revolution in mental health and mental retardation practices occurred. Beginning in the 1960s, there was growing evidence, increasingly accepted by policy makers, parents, and professional service providers, that residential institutions were incapable of providing adequate treatment and were inherently restrictive environments in which to live. By 1970, when the population of residential institutions was at its peak, the alternative of institutional placement was beginning to be eliminated. In New Hampshire, children were no longer readily accepted at the State School, and the annual number of discharges began for the first time to exceed the number of admissions.

In the early years of this revolution, children were discharged who were mildly disabled. These children most often went back to live with their natural families and attended a special school with other handicapped children. A significant number of the children who left in the early part of the decade did not attend school at all,

because there were no legal mandates that they do so and because local public schools were not capable of meeting their special needs. In more recent years, the children who have left the institution have been more likely to have significant and multiple impairments, and they have been less likely to return to their own families for care. Due in part to the implementation of statutory mandates and judicial orders, and in part to improved treatment technologies and increased public funding, these severely disabled children have been more likely to attend school in their local communities and to receive the services necessary to enable them to more fully participate in normal society.

These trends in New Hampshire are similar to trends in the few other regions that have documented the experiences of deinstitutionalized children. In general, there has been very little analysis of children's experiences when they are moved from an institution into the community. We know much more about the circumstances faced by adults than we do about those faced by children. Without the availability of a larger data base to make comparisons, we cannot claim that our findings are representative of the experiences of deinstitutionalized children in other places. We hope that others will raise questions similar to those explored in the present study so that such a comparative data base can emerge to guide future policy making efforts.

Characteristics of Those Children Who Left and Those Who Stayed

In examining the physical, social, and intellectual characteristics of the children who left the State School before they became adults, it was clear that they differed in several significant ways from those children who remained at the School. In general, the children who left (Population One) were less severely intellectually and physically impaired than their age peers who remained (Population Two). At the time of admission, there were more severely and profoundly retarded children in Population Two than in Population One. Although children in both groups were admitted to the State School at roughly the same age (about eight years old), those in Population One left after an average residency of five and one-half years while those in Population Two who eventually left as adults did so after an average stay of almost 14 years.

The two groups also differed in areas important for social interaction such as the ability to speak, the ability to respond to other people in the immediate environment, the presence of inappropriate stereotypical behaviors, and the ability to read and write. Children who were less impaired in all of these areas were more likely to return to their home communities. Those who stayed were also more likely to have one or more major medical conditions that required frequent attention. Characteristics that appear not to differentiate those who left from those who stayed include sex, the ability to walk independently, the ability to dress, feed, and toilet independently, the level of frequent aggression, and the presence of cerebral palsy or severe vision and hearing impairments.

These similarities and differences lead us to the conclusion that factors related to social interaction are more powerful predictors for community placement than factors related to independent functioning. In other words, children who can get along with others and communicate effectively are more likely to leave an institution than those who cannot do these things. Even if a child requires a great deal of assistance in the basic areas of dressing, feeding, and toileting, he or she will leave the institution sooner if he or she is relatively socially adept. (See the case histories of Kerry Gagnon and Daniel Martin regarding this contrast.)

Children who left the State School in more recent years were significantly more handicapped than those who left in earlier years. In the period from 1979 to 1985, 70.3 percent of the children who left were profoundly mentally retarded. This was a 300 percent increase over the proportion of profoundly retarded children who left between 1970 and 1976. Over 70 percent of those who left from 1982 to 1985 had at least one major medical problem. Over 80 percent had no intelligible speech. One-half could not move about independently. In general, the children who left the State School and institutions in other states were more severely impaired than the adults who left during this time period.

These data indicate that by the early 1980s, degree of severity of a child's handicapping condition was not a major factor in whether or not that child left the institution. Although Population One was less impaired than Population Two taken as a whole over the 15 year period, these differences tended to fade in recent years. Even the

most severely physically and intellectually impaired children were leaving the institution in the years after the 1981 federal court order. However, social and emotional disturbances continued to act as barriers to community placement in this later period.

Family Characteristics

The family circumstances for these two groups also differed. Children who left the State School were more likely to have come from lower income families with less formal education. However, the families of both groups of children were upwardly mobil in terms of job status during the period of their children's residence. Those families who initially held lower status jobs experienced the greatest amount of upward mobility. In general, both sets of families belonged to lower and middle income groups. Almost no upper-middle or upper income families were represented in the samples. The two groups of families were also similar with regard to size, with most families consisting of two parents and four children. Of 58 families for whom data were available in Population One, 12 (20.7%) had more than one developmentally disabled child, an extremely high proportion.

When the children in both populations were initially placed at the State School, the vast majority were living with their natural families, although those children who did not eventually leave before becoming adults were almost twice as likely to have come from a foster family.

These findings are consistent with earlier research into the socioeconomic backgrounds of institutionalized people. It is to be

expected that lower income families whose disabled children are placed outside of the home rely on public facilities. And, consistent with the work of Farber (1959, 1968), it is to be expected that low socioeconomic status families are more likely to accept their children back into their homes after a period of institutional residency. Farber's explanation for this finding is that lower income families view the presence of a disabled child as only one of a series of difficulties with which they must cope. Middle and upper income families are more apt to view the child's presence as an obstacle to economic advancement and as a singular crisis with major consequences.

Other data indicate that families of Population One were more likely to remain in contact with their children during the period of residency, either through visits to the School or by bringing the child home for brief stays. There appears to be less of a "rejection" of the children in Population One. Again, this is consistent with the notion that lower income families make adjustments in order to cope with one more problem rather than taking what Population Two families may view as permanent steps to eliminate the problem. This argument should not be construed as a condemnation of Population Two families. Their children were more severely handicapped to begin with, and they were encouraged from several sources to initially place their children at LSS. These would be important factors in the subsequent decision to have the child leave the institution. It could also be argued that Population Two families, with more education and more financial resources (and,

therefore, with more perceived clout), were more successful in resisting pressure from State School staff and community care managers to place their children out of the institution. Population One families may have been less articulate and less able to control the decision making process when their children were identified as candidates for community placement.

The upward mobility experienced by both sets of families is interesting, and may simply reflect the generally improved economic conditions of most families over the past 15 years. However, a question arises concerning the economic benefits that may be experienced by families that choose to place their children in a public residential facility. If there is a perception that institutional placement is of economic value to families, they may continue to advocate for institutional care.

Reasons for Admission to the State School

The primary reason for admission of a child to the institution was extreme behavior leading to an inability of the child's mother to continue to provide care. Overall family stress and the lack of alternative living arrangements and local school programs were also commonly cited reasons for both sets of families. Population One children had significantly more behavior problems leading to admission, and these children were also significantly more likely to have been abused or neglected prior to admission.

These findings are related to the respective groups' diagnoses. The Population One children were more intellectually intact, more verbal, and more social. Thus, they were more capable of causing behavioral control problems for their parents. These problems occasionally led to abuse and often led to the decision to institutionalize the child. The lack of respite care for these disruptive children may have also led to institutional placement. Although few parents cited this as a primary reason for seeking admission for their children, several parents commented in other contexts about this problem. The State School offered some respite care in the early and mid-1970s, but it was limited to a single 30-day period once a year. Shorter stays several times a year were not an option. Parents viewed this as not meeting their needs, and usually chose not to take advantage of it.

The reasons for placement expressed by parents in our study echo those reasons given by parents in similar investigations. In the Search and Find project conducted by the Division of Mental Health and Developmental Services in New Hampshire in 1979, a review of 41 admissions led to the following conclusion:

> The management of maladaptive behaviors coupled with other life management needs puts severe stress on families and service agencies that are not necessarily well equipped to deal with the problems. Family and service agencies are lacking the skills and resources to deal with behavioral crises and/or life management problems of a severe and/or long term nature. These problems wear down families and staff who after lengthy efforts, simply feel that the institution is the only solution. Unfortunately, the only alternative is the institution and unless [the child is] placed in an ICF unit, little behavioral training is available. (Action for Independence, 1980, p. 121) .

The fact that these stresses have been so thoroughly documented has had distressingly little effect on social policies which require families to maintain their children at home. The removal of institutional care as an option for families has intensified the need for family support through respite care and other means, but these needs remain largely unmet.

Region of Origin and Placement

We determined the region of the state in which members of the two populations lived at the time of admission. We did not specifically determine the region into which the children in Population One were placed, but in general such placements returned children to their "region of origin." Children from Population One came from urban, southern, and central communities such as Laconia, Plaistow, Derry, Manchester, and Salem. These happen to be the areas in which pilot case management systems were establised in the late 1970s. It appears that the availability of community case management is associated with the increased probability that a resident would leave the institution at an earlier age. Members of Population Two came more often from northern, rural communities or those places in which case management was established at a later point in time, such as Littleton, Keene, and Nashua. The small numbers of children in the two groups and their relative dispersal around the state preclude definitive statements about the effect of geographic location on the deinstitutionalization process.

Residential Placements

When members of Population One left the State School, they went to live with their natural families (46.3%), in foster homes (17.9%), in group homes (19.4%), or in other arrangements (16.4%). These findings, which are based on the group as a whole over the 15-year period, are comparable to findings from a similar study in Massachusetts in the mid-1970s (Wyngaarden & Gollay, 1976) and quite different from a more recent Massachusetts study, in which only 6.6 percent of the children returned to their natural families and the remainder lived in foster care or group homes (Seltzer & Krauss, 1984). Only two of the New Hampshire children went to adoptive homes. In general, adoptive and foster homes were underutilized in this sample. This finding is a cause for concern given that many experts in the field of developmental disabilities view group homes as less desirable alternatives than adoption, foster care, or natural family placement (Roos, 1978).

The type of placement did change over time. In more recent years, fewer children went to live with their natural families (3 out of 31 placed after 1978). But there was no increase in the use of foster or adoptive care. Group homes became the predominant placement option over time.

The size of the residences into which children were placed ranged from 4 to 6 residents for half the sample to 7 to 10 residents for one-quarter of the sample. Discharged children generally went to live in smaller residences than was the case for the sample of 119 children and adults included in the 1979 Search and Find survey. In

later years (after 1978), children were more likely to be placed in group facilities with more than six residents. In the years before 1978, placement was more often in smaller residences with six or fewer people. Thus, in more recent years there has been greater reliance on out-of-home care in relatively large group homes.

If a child was placed in a group facility, it was equally probable that he or she would live only with other children or with a mixed group of children and adults. Very few children went to live in adult-only facilities.

Stability of Residential Placement

As a whole, children lived in their community residences, whether they were family homes, group homes, or other institutions, for three to four year periods. This average is somewhat longer than we expected. Given the behavioral and educational difficulties that many of these children manifest, we thought that they would move around more frequently. Although this average length of stay shows relative stability in residential placements, a closer look at individual situations reveals some cause for concern. One-half of all the initial placements lasted less than one year.

Almost one-third (31.3%) of the initial placements failed in the sense that these children returned to the State School. As in the original admission to the School, the reason for placement failure was very often (65% of the returns) due to extreme behavior problems. Most of the returns to LSS (60%) were initiated by the child's parents, whether or not the child was actually living at home. If

a child returned to the School after an initial period of community living, he or she was likely to stay there for a period of one and one-half years. Again, we can detect important historical changes at work, in that almost all of these failed community placements occurred before 1976. Since 1979, only two of the children in our sample returned to the School.

One-half of the children lived in more than one community placement after they left the State School and before they became adults. Just over one-quarter of the children had more than two community placements. Less than one-tenth of the sample had more than three placements. If a child experienced more than one community placement, it was less likely that he or she would be returned to the State School. It seems that changes in community placements acted as an alternative to reinstitutionalization.

We also found that changes in community placements were likely to be in the direction of group homes, away from natural families. In more recent years (since 1982), no children have either left the institution to live with their natural families or moved from an out-of-home placement in the community back into their family homes.

One of the central questions of this study had to do with the direction of movement as children left the institution and subsequently lived in one or more community settings. We assume that the institution is the most restrictive environment available, and that natural family homes are the least restrictive (from the child's perspective), with adoptive homes, foster homes, group homes, and small regional institutions completing the continuum of

"restrictiveness," in that order. Given this simplified model of restrictiveness, we could say that in the later historical period and as children moved from one placement to another, they were more likely to live in relatively more restrictive environments. However, this generalization must be qualified by emphasizing that the return rate to LSS decreased markedly over time, and alternative community living arrangements were being developed that offered options to families so they would not have to bear the primary burden of caring for their disabled children. In addition, children who left LSS in later years were more severely impaired than those who left earlier.

Restrictiveness must be viewed not only from the child's point of view, but also from the family's. If the presence of a severely disabled child prevents family members from continuing their own development, and interferes with economic and social stability within the family system, then placement in the natural family is a restrictive option for some families.

One option that would help to resolve this dilemma would be greater availability of adoptive and foster care. Such an arrangement would be relatively less restrictive for the child, when compared to group homes with six or more residents (as was the case in later years) or other institutional settings such as residential schools or nursing homes. The natural family would be relieved of the burden of caring for their handicapped child, but could maintain close contact with their child if he or she were in a family-like setting nearby. Properly subsidized and supported substitute family care has not been available or utilized for our sample and for other children and families in similar circumstances.

Services Received During Community Placement

Once children left the State School to live in a community setting, they received a variety of medical, therapeutic, habilitative, and social services. During the initial community placement, over half the sample received (in the order of frequency) transportation, medical diagnoses, public welfare assistance, recreation, speech and language therapy, and case management. Less than one-quarter of the sample received specialized medical care such as dietary intervention, surgery, and dental care, respite care, and special vocational programs such as participation in a sheltered workshop or work activity center. Needs that are probably universal that were least likely to be addressed were dental care (provided to only 14.2% of the sample) and respite care (provided to only 20.7% of the families in the sample). There were no significant changes in the frequency of service provisions if a child moved from one community placement to another.

Parents rarely were required to pay for these specialized services. When parents did pay, it was for diagnostic services, psychotropic medication, surgery, and dental care. A small number of parents also paid for respite care, when it was available. One explanation for the low use of dental care may be that it was the least subsidized service, with over half of the parents who used it having to pay for it out of their own pockets or with private insurance. It should also be noted that parents whose children moved to a second or third community placement were much less likely to pay

for medical or other services. For example, no parents had to pay for dental or respite services during the second or later community placements.

Two "generic" services that were used frequently by children were recreation (used by 60.3% of the sample during the first community palcement) and transportation (used by 74.6% of the sample during the first community placement). It appears that these services are relatively well established and are available to a large portion of deinstitutionalized children.

On the other hand, vocational training opportunities were relatively rare. Only 28.6 percent of the sample received prevocational training during the first community placement; this increased to 39.3 percent of children who went to a second placement. Work activity programs and sheltered workshops were used by one-tenth to one-fifth of the sample, respectively. Given that the average age of the children at placement was 13 years, with many of the children in their mid- to late teens, it would seem that prevocational and vocational training opportunities would be important parts of the treatment plan.

Another important service is case management. Only about one-half (52.4%) of the children were provided case management during the first community placement. This improved slightly (to 60.7%) during second community placements. Given the central role in the placement and treatment process played by case managers, these levels can be regarded as less than adequate. This finding may be related to the relatively high return rate experienced by children during the first

community placement. With no one professional responsible for procuring and monitoring appropriate services, the likelihood of a failed placement would increase. Although public schools are not mandated to provide case management per se, and the decision by area agencies to provide case management to children is a local option, there seems to be a professional consensus that case management is the glue that holds an individual child's treatment plan together.

Like other variables in this study, this one is also subject to historical factors. Prior to 1978, there were almost no formal case management services available. By 1985, they were available on a universal basis to developmentally disabled adults and on a less than universal basis to children. We found that all children in our sample placed out of the institution since 1981 have been assigned a case manager.

In fact, several important services increased in their availability over time. Comparing the pre-1979 placements with those that occurred in 1979 or later, we found significant increases in the provision of psychotropic medication, occupational therapy, speech therapy, physical therapy, and case management. Again, these findings must be considered in light of the fact that more severely handicapped children were being discharged in the later years. Greater use of services may also be related to greater availability of case management, as one of the functions of this service is to assure that the other needed services are obtained. In any case, there is clearly a relationship between the increased availability of services and the historical period in which placement occurred. And

the critical historical factors that would play a role here are the implementation of federal and state service mandates in 1978 and the issuance of the federal district court order in 1981.

Educational Placements

Type and Stability of Educational Placement

When children left the State School, they usually were initially placed in a special non-residential school for handicapped children or a self-contained classroom in a regular school. However, a significant portion of children (22.4%) were not placed in any school after leaving LSS. Fewer children changed educational placements than changed residential placements, although 41.8% changed educational placements at least once and 17.9% changed placements at least twice. As children changed educational settings, they were more likely to be placed in self-contained classrooms in regular schools and less likely to continue in non-residential special schools. Very few children received their education in regular classrooms, special residential schools, at LSS during the day, at home, or in other residential institutions.

During the first community placement, most children attended school in their local communities. Over half (61.5%) of the children attended public schools in their home districts, while the remainder (38.5%) were assigned to private schools or other public schools outside of their home districts.

The length of educational placements averaged 2.2 years in the first placement, 2.9 years in the second placement, and 3.8 years in the third placement. As with residential placements, the individual variation in length of stay was considerable, with almost half of the initial placements lasting less than one year. Children who changed educational placements tended to stay in those subsequent placements for longer periods of time. The relatively shorter length of stay in educational vs. residential placements is probably due to the fact that an appropriate educational program was sought only after a residential placement had been arranged.

In addition to the services described in the previous section, we also assessed school-based services such as vocational special education and training in self-help skills (also known as activities of daily living [ADL]). We found similar patterns here with respect to school-based vocational training, in that only about 10 percent of children who attended school received any vocational special education. On a more positive note, about two-thirds of children in school received ADL training.

When children changed educational placements, it was most often due to extreme behavioral problems, changes in the child's residential placement, growing too old for a program, or a desire to place the child in a more socially integrated setting. Unlike parents' roles in residential changes, parents rarely initiated changes in their children's educational placements. They more often played a passive role of approving a change in placement but not questioning its value or appropriateness for their children. This passive role is

manifested in the fact that only one due process hearing occurred for the members of our sample. In light of the severe behavioral needs of the children and the relative scarcity of school services for this population, we expected more frequent formal disputes between school districts and parents. This low level of dispute may be related to a low level of expectations on the part of parents. Prior to 1978, there were no due process protections for children and their parents in the educational decision making process. After 1978, protections were available, but children were less likely to live with their natural parents, reducing the probability that a formal complaint about a child's schooling would be registered. A counterargument would be that the schools were providing an appropriate program, but the data available from the AGH study does not support that notion.

Historical Changes

The major trends associated with time were that (1) there were significantly fewer incidences in which a child received no educational program after community placement, and (2) children were more likely to receive educational services in their local districts. For example, during the years 1970-1972, almost half (47.8%) of the children who left LSS were not assigned to any school. By the 1976-1978 period, that proportion was down to 14.3 percent. In the most recent cohort (1982-1985), all children were placed in an educational program after leaving the institution. Likewise, during the earliest

cohort, half of the children who attended school did so in an out-of-district placement. In the middle cohort, one-third of the children were in such placements. And in the most recent cohort, only one-quarter of the children attended school outside of their local districts. This is particularly important considering that the children in this most recent cohort were significantly more severely impaired than those in preceding years.

However, there were no significant differences in the type of educational placements (segregated school, self-contained classroom, etc.) over time. This leads us to the conclusion that at one level the degree of restrictiveness decreased over the 15 year period. That is, children were more likely to attend school, and to do so in their local communities. At another level, the degree of restrictiveness could be said not to have changed in that opportunities for social interaction with non-handicapped peers did not increase. One of the central purposes of federal and state special education mandates has been to assure that handicapped children participate in integrated educational activities with non-handicapped children. In general, this intent has not been achieved. Although deinstitutionalized children are receiving a free public education, its appropriateness may be questioned in light of this finding.

This conclusion is supported by the results of the study by AGH Associates. In the Spring of 1985, the New Hampshire Special Education Bureau contracted with AGH Associates to evaluate the quality and appropriateness of the individual education plans (IEPs)

developed for deinstitutionalized children attending local public and private educational programs. In their review of 20 children's IEPs, they found that the IEPs were either nonexistent (30 percent of the cases), or incomplete (up to 85 percent of the cases in which IEPs existed). The IEPs did not establish the crucial link between the child's assessed needs and the development of an appropriate instructional plan. Services identified as necessary on the IEPs were not being provided. Less than half of the children were in public school programs (a lower proportion than we found in our most recent cohort), and only one child had any opportunity for interaction with non-handicapped children during the school day. Related difficulties in program implementation included inadequate medical care for the children, overuse of psychotropic medications, inadequate planning for the transition from the State School to the local program, and inadequate training and technical assistance for local staff. These findings support our conclusion that the letter of policies and court orders has been met in that children have returned to their local communities and been placed in educational programs, but the intent of these policies to provide appropriate and socially integrated programming has not yet been achieved for most deinstitutionalized children.

The Effects on Families of Deinstitutionalization

The ways in which families respond to the deinstitutionalization process depend upon the original circumstances of admission, the

experiences of the child and family during the period of institutional residency, the severity of the child's handicapping condition(s), the historical period in which both admission and subsequent placement occurred, and the availability of formal and informal support networks. In general, parents have had little say with respect to the placement and treatment process. Professionals and policy makers have determined the type and locale of services, and parents have had to adjust to those decisions. During the 15 year period of deinstitutionalization documented in this report, parents have been faced with rapidly changing assumptions and policies relative to the care of their handicapped children. What is remarkable is the ability of parents to accept these changes, see their intended benefits, and sustain an essential faith in their own children's development and in the capacity of professionals to make good judgments.

At the time of admission to the State School, parents received strong encouragement from physicians, psychologists, and social workers to place their children out of the home. Not only did these professionals view this option as in the child's best interests, they also felt such a decision was necessary to preserve the family's well-being. Mothers in particular were viewed as at risk for serious emotional and physical illness if their disabled child remained at home. Both mothers and fathers agreed with this view, stating at the time of admission that continued care for the children at home would lead to exhaustion, depression, and neglect of other family members.

Parents from the two research populations faced somewhat different circumstances at the time of admission. The average year of admission for children in Population One was 1970; for Population Two the average year of admission was 1965. For the latter group, institutional placement was seen as an acceptable, common practice. Admission was relatively easy, although waiting lists meant either some delay in the process or use of alternative temporary facilities such as the state psychiatric hospital. The placement was expected to be either long term or permanent.

For Population One parents, admission was not so easy or acceptable. By 1970, in an effort to discourage parents from choosing this option, the State School was no longer maintaining waiting lists. The requirements for admission were becoming more stringent, and the possibility of the child's subsequent return to the family was made explicit. The state adopted a specific policy to reduce child admissions and begin returning children to their local communities. Thus, families seeking institutional placement in this later era were swimming against the tide. However, local educational and residential services were still a long way from becoming established. Thus, the two-option system (home or the institution) was still in place, but parents were being told implicitly and explicitly that institutional placement was no longer the best possible choice.

This initial difference in the historical circumstances of admission had other consequences. Once the placement occurred, Population Two parents were significantly less likely to maintain

contact with their children through visits to LSS or by bringing the children home for brief periods. And, given the way we defined the two populations, children in this group remained at the institution for much logner periods of time (an average of over 14 years for those who eventually left).

Both sets of parents were initially opposed to the possibility of their own children's community placement and to the deinstitutionalization of mentally retarded people in general. However, parents whose children left the State School tended to change their views significantly. After a period of community living, parents of deinstitutionalized children expressed much more support for both the general concept and for its application to their own children. They believed that their children were happier and that their own families had not been adversely affected by the placement. Parents whose children left LSS after 1978 were clearly more enthusiastic about community placement than parents whose children left in earlier years, reflecting a belief on the part of parents that the service delivery system had indeed improved over the years.

Parents whose children left the institution generally believed that there were adequate community services available. Parents whose children remained at LSS were more skeptical about the availability of such serivces. Neither group was confident that funding for community services would continue for the long-term future. This lack of confidence was clear in the remarks made by parents

concerning their inability to care for their children if community facilities were to be closed, the effect their own aging would have on their ability to care for their children, and the lack of community acceptance of their disabled children. These anxieties were balanced by the immediate satisfactions described by parents who saw their children acquire new skills, become more independent, and enjoy life in the community.

Conclusions

These findings concerning children who left the institution during a time of significant change in social policies, children who remained at the institution during this period, and the families of these two groups of children allow us to draw some conclusions about the effects of social policies on severely handicapped children. We offer the following statements based on the results of our investigations:

1. The population of children living at the State School has declined from about 350 to almost zero in the past 15 years.
2. In the early years of the deinstitutionalization movement, a significant portion (almost one-third) of children's community placements failed. But no child who left LSS in the past three years has had to return to the school.
3. Even the most profoundly handicapped children have had opportunities to return to their home communities.

4. In recent years, children have been less likely to return to their families and more likely to live in some other out-of-home arrangement, often with six or more other disabled people.
5. In recent years, children have been more likely to attend school after leaving the institution, and that school is more likely to be a public one located in the child's home community.
6. Children either stay in the initial residential and educational placement after leaving the institution, or change placements only once or twice (until they become adults, that is).
7. If a child changes his or her educational or residential placement, the frequency of such change is limited to once every two to three years, on the average. The most common reason for either returning to LSS or changing placements is extreme behavior difficulties.
8. Parents have often been the ones to initiate changes in residential placements, but rarely are involved in changes in educational placements.
9. Parents have had to pay for relatively few of the services required by their deinstitutionalized children, with the major exception being in the area of medical and dental care.
10. Educational and related services have become more available in recent years, especially since the implementation of federal and state special education mandates in 1978 and the issuance of the federal court order in 1981.

11. There are still few social supports for families with severely handicapped children. Counseling and respite care are particularly rare.

12. Parents' attitudes toward the deinstitutionalization of their children have become considerably more positive as a result of witnessing the benefits of community-based care. However, they remain anxious concerning the permanence of this care.

13. Social policies that relied solely on institutional care, and more recent changes in those policies that encourage community care, have been themselves sources of pain and stress for parents. Changes in policies have occasionally exacerbated rather than ameliorated the pain and stress associated with having a handicapped child. However, when such changes lead to real improvement in the services received by their children, and to positive changes in their children's development, parents seem willing to overlook the past pain and work hard and cooperatively toward future gains.

14. Litigation based on legislative mandates may be a more powerful impetus for reform than legislative mandates alone. Although we detected significant changes in the experiences of deinstitutionalized children after the implementation of PL 94-142 in 1978, we observed even clearer improvements after 1981, when the court order was issued as a result of a law suit against the institution and the state. These improvements were noticeable in spite of the fact that the children who left LSS in this most recent period had more complex and difficult needs than those who left in earlier periods.

15. The intent of social policies, and the regulatory and judicial fallout from those policies, has not been fully achieved. Although tremendous changes have occurred, issues of full social integration, the appropriateness and accessibility of services, and the creation of truly family-like living arrangements remain to be resolved.

All this means that the deinstitutionalization of children has been enough of a success to justify its full continuation. Its flaws are repairable, in light of the evidence presented here that improvements in policies and practices are possible. Further improvements will depend on a full commitment from policy makers, professionals, and parents. Calls for the renaissance of institutional models of care are premature, not founded on empirical evidence, and rooted in political considerations rather than a commitment to the full development of all people. We can say that "deinstitutionalization" has occurred successfully, but the broader goal of full social integration, referred to as "communitization," has not been fully achieved. Given the correlation between social policy reform and improved outcomes for children and their families documented in this report, it is evident that continued efforts will yield continued improvements.

Chapter Ten

Social Policy Recommendations

The ultimate purpose of our investigation of the consequences of deinstitutionalization has been to assess the success of social policies affecting handicapped children and their families. Because one of the most significant and sensitive areas of recent social policy has been the shift in locus of services from institutions to community-based facilities, the reintegration of previously institutionalized children has provided one measure of that success.

As we indicated in the previous chapter, there is a good deal of evidence that the social policies that evolved in the 1970's have succeeded. However, lessons learned in similar social policy arenas cannot be ignored. In the late summer of 1985, the American Psychiatric Association declared the deinstitutionalization of people with psychiatric disorders a "major societal tragedy" and a "disastrous" failure (New York Times, September 13, 1985). The almost total absence of adequate community support services for this population led to as much exploitation and developmental harm outside of institutions as had occurred previously inside them. There is a real danger that the judgement that deinstitutionalization of psychiatric patients has failed will be generalized to the experiences of people with mental retardation. The recommendations offered here are an attempt to prevent such generalizations and to advance the process of communitization of people with mental retardation so that both the intent as well as the letter of laws and court orders may be achieved. Our recommendations are as follows:

1. Develop State-wide Longitudinal Management Information Systems for Previously Institutionalized Individuals

One of the most glaring problems that emerged in the early stages of the research project was the lack of centralized data on previous residents of Laconia State School. When we initially approached LSS administrative staff to learn the potential size of the research population, we were told by various people that the number of children who had been discharged since 1970 was somewhere between "a handful" and 200. When we sought the assistance of the Division of Mental Health and Developmental Services in locating potential subjects currently in the community-based service system, we learned that the state-level management information system was incapable of such a task. When we approached local service providers (primarily case managers), we found that local data bases were not well developed and the manual process of identifying ex-residents of LSS would be quite burdensome.

There are valid reasons to be very cautious in the development of centralized data bases on specific groups of citizens. Our perspective as social scientists creates a bias in favor of such information because it makes the research task that much easier and the data more valid. But there are other, more justifiable reasons for such a data base. The question of under what conditions and how to care for people with developmental disabilities has never been fully resolved in the United States. The cyclical nature of the history of the care and treatment of such individuals indicates that this is a policy area frought with uncertainties. Changing values, economic conditions, political ideologies, and treatment technologies have led to changes (not always

advances) in social policies. Although we recognize that longitudinal data bases will not (and should not) become the sole source of decision making in this field, decision making in the complete absence of empirical information cannot be justified.

The danger of intrusive information systems can be counterbalanced by careful maintainence and protections that assure that the privacy of individual citizens is not violated. Research branches located within state agencies can collect and maintain such longitudinal data, as has been the case in New York over the past several years. Disclosure of personally identifiable information outside of that system can be limited in appropriate ways. But there must be some mechanism for learning how either static or changing social policies affect the people they are intended to help. Without such knowledge, decisions are made in the dark and are too easily controlled by the forces of political expediency and ideology.

2. Create Mechanisms to Help Families Make Informed Decisions

Just as policy makers need accurate data in order to make good decisions, family members, particularly parents, need complete and accurate information in order to know best how to meet the extraordinary needs of their disabled members. This report has illustrated the pressure faced by many families whose children placed extreme demands on mothers, fathers, and other family members. Until quite recently, and continuing to some degree in the present, parents viewed their options as two-fold. Either keep a severely disabled child at home or place the child in a public residential institution. In the absence of any incentives to keep the child at home (other than personal commitments

to meet one's obligation as a parent), parents felt coerced into institutional placement.

Since the early 1970s, and particularly since Judge Devine's court order in 1981, institutional placement has not been an option for families. At the same time, community-based options have been limited primarily to adult group homes and small non-public institutions. Other alternatives such as adoption, temporary or permanent foster placement, long-term respite care, or supervised semi-independent living arrangements have begun to be developed, but their availability has not been made known to parents. In addition, the use of preventive and habilitative services such as early intervention programs, local school-based special education, vocational training, and school-to-work transition support is becoming increasingly available.

These short-term and long-term alternatives to institutional care and full-time home care must be made known to parents and to the people who help parents decide what to do about caring for a severely disabled child. Parents have a right to be fully informed about what is available, and their choice of some of these options will serve to stimulate the further expansion of appropriate alternatives.

3. Support Policies and Programs Aimed at the Prevention of Institutionalization

There are several ways to reduce dependency on the option of institutional care, which is a goal we endorse for both humane and empirical reasons. One of the ways, documented in this report, is to enact and enforce social policies that treat institutional care as a last resort. As we said in Chapter Nine, those social policies are in place

and are having some measure of success. The major constraint on the success of these policies is lack of full funding up to authorization levels. Neither the federal nor state legislatures have appropriated enough money to fulfill the commitments articulated in special education mandates (see Chapter Two). At the state level, one step that could reduce dependency on institutional care or other forms of out-of-district placement would be to provide full appropriation for the Catastrophic Aid program. This would create a major incentive to local school districts to maintain severely and multiply handicapped children in their own schools.

Another approach to preventing institutionalization is to determine the historical reasons for institutional placement and then try to respond to those reasons. There seem to be two reasons for placement that may be responsive to social policy.

The first is the lack of community-based support for families with children who require extraordinary care. As this is a large and complex area of discussion, we will address it in detail in a separate section below.

The second reason is related to the characteristics of the particular child. This study, like others, found that extreme behavior difficulties are a more prevalent cause of institutionalization than extreme medical needs. It is also true that behavior difficulties are likely to be the cause of subsequent changes in community placements or return to the institution. One of the popular rationales offered for continued use of institutions is that there are some children who are so medically fragile that they cannot remain at home or in other community

settings near their families. This rationale is not supported in the present study. When parents were asked why they made the initial decision to seek placement at the institution, problems with behavior were mentioned much more frequently than medical concerns.

This implies that assistance to families must emphasize behavioral management techniques. Although a small number of children will also require nursing attention, the greater portion of children at risk for out of home placement require a variety of behavioral control approaches. This might include live-in assistance similar to the personal care attendants used by physically disabled people. As well, unrestricted use of respite care can relieve families of the constant burden of dealing with unpredictable, bizarre, or aggressive behaviors. Conservative and carefully monitored use of psychotropic medications can also provide some relief for both the family and the individual.

4. Create Incentives and Fully Enforce Policies That Lead to Increased Social Integration in Educational and Residential Settings

The historical trends evident in New Hampshire indicate increased physical proximity of handicapped children to non-handicapped peers and adults. Children live and attend school in closer proximity to normal society than they did at the beginning of the 1970s. But their particular school and living environments still remain out of the mainstream. Children tend not to live in natural family settings (including adoptive or foster care) nor do they spend much time each day with people who are not disabled. While the institutional population of children has been dispersed to community settings, it seems that even in these local programs, handicapped children tend to be congegrated together in relatively isolated environments.

There are numerous examples of successful community integration of severely handicapped children. For example, the University of Connecticut has provided leadership in assisting local high schools to integrate severely handicapped children (some of whom once were institutionalized) into regular classrooms. Technologies have been developed that address teaching appropriate social interaction skills, training teachers to accommodate the needs of severely disabled children, preparing non-handicapped students to act as tutors of their disabled classmates, and modifying administrative practices to incorporate a broader range of children in public schools (see for example Certo, Haring, & York, 1984).

In a related vein, a great deal of attention has been drawn recently to the role of high school curriculum in preparing handicapped youth to move into the world of competitive employment and independent living. Our finding that special vocational education and on-the-job training were rarely utilized indicates that there is still much work to be done here. There are some existing models in New Hampshire (e.g., Portsmouth High School) and the N.H. Developmental Disabilities Council has recently assumed some leadership in the stimulation of "transitional" programs. These efforts must be continued and expanded. Vocational training programs (rather than sheltered workshops) provide natural and productive opportunities for the integration of disabled youth and young adults.

The major barrier to successful school integration is neither knowledge nor technique; it is public attitude and resistance from pockets of uninformed administrators and teachers. These latter constraints can be overcome through aggressive leadership from the state

Department of Education and through training and technical assistance to local schools. It is assumed that once professionals attitudes are changed, and success is demonstrated in the schools, then public attitudes and support will follow.

It should also be noted that there is no evidence that the role of financial considerations is clearly understood. In general, school administrators prefer to educate their severely handicapped pupils within their own buildings rather than contracting with private vendors. This preference is based on the perception that costs of local programs are lower and easier to monitor. But the cost of true integration, which requires smaller class sizes, increased availability of therapists working in classroom settings, some physical remodeling of school buildings, and more training for regular and special teachers may offset these savings. It cannot be argued that true integration is more or less expensive than either institutional care or community-based care that perpetuates social isolation. Thus the decision to provide full integration must be based primarily on an assessment of handicapped children's developmental needs and their legally protected right to education in the least restrictive environment.

Integration in residential settings must also be addressed. The recent trend to place deinstitutionalized children in homes with six or more residents is a cause for some concern. The large number of children who lived at Laconia State School who had no ongoing contact or legal relationship with their parents indicates that this group is especially vulnerable to social isolation and abridgement of their right to live in mainstream society. Currently the provision of residential care for

children who live outside of their natural homes is the responsibility of the state and local adult-oriented developmental disabilities service delivery system. And the incentives for continuing care in natural families or adoptive placement are minimal. There must be a two-edged approach that 1) mandates that out of home placements for children occur in small residences (with no more than one or two other disabled people present) and 2) supports natural and substitute families who choose to care for severely disabled children in their own homes. This latter policy issue will be addressed more specifically in the next set of recommendations.

5. Create Multiple Approaches to the Support of Families of Deinstitutionalized Children

There are two areas to be considered relative to supporting families. The first is the design of supports aimed at families whose children are in the process of moving from the institution back to their local communities. The second is the support of families whose children live at home or closeby and who would be at risk for institutional placement if adequate local supports were not available. The present study casts some light on the former area, and raises some questions relative to the latter.

Most families have a strong desire to be intimately involved in their children's institutional care and in any decision to move the child out of the institution. In both the Daniel Martin and Kerry Gagnon case studies included in this report, the role of parents (in this case fathers) was clearly illustrated. On the one hand, parents may advocate for both improved institutional care and discharge as soon as possible,

even when their children have very severe behavioral and physical difficulties. On the other hand, parents may view institutional care as quite adequate and argue against community placement. Ironically, in both situations we found institutional staff taking the opposing view. This indicates the need for open and frequent communication between parents and professionals concerning the immediate services being received by institutionalized children and the longer term plans for placement. Specifically, there must be opportunities for:

1. Early and continuous involvement of parents in decisions affecting treatment, placement, and long-term goal setting for their children
2. Completely open access to a child's treatment program, including unscheduled observations, frequent parent-staff conferences, and awareness of the purposes and effects of specific treatment approaches
3. Visits to proposed community placements and input as to their potential value for their children and convenience for them as they maintain close contact after the placement occurs
4. Personal communication with other parents whose children have been through similar transitions to learn of possible pitfalls that will be encountered and of ways to cope with the stress associated with community placement
5. Ongoing involvement in their children's program after placement has occurred, including the awarding of complete or partial guardianship to parents in the case of children over 18 who are legally incompetent (i.e., natural parents should always be the first candidates considered if guardianship is being contemplated)

Many of these recommendations are already in place. The Client Centered Conference required for those who participate in the developmental services system is a mechanism for incorporating parental involvement. But our experience is that such a formal proceeding does not guarantee that parents play a meaningful and equal role in the decision making process.

The role of personal financial cost must also be assessed. One approach would be to set a policy goal of making the location of care a cost-neutral issue. In other words, the choice of in-home vs. out-of-home care should lead to neither savings nor costs for families. If this were the case, then placement decisions would be independent of family financial constraints or goals. Upwardly mobile middle class families should not be financially punished for having their children return home (or remain at home in the first place), and lower income families should not be forced to choose between meeting basic family needs or bringing their disabled children home from the institution. To go a step further, the range of out-of-home options should also be cost-neutral. That is, the use of adoptive or foster care, group homes, or residential institutions should not present differential costs to families. Such a policy principle would remove a good deal of the personal stress associated with placement decisions.

Turning to the issue of supporting families whose children have already returned home or whose children never lived at the institution but who would be at risk for such placement, we find much has been said about this topic. One of the most recent and cogent analyses is provided by the Human Services Research Institute (Agosta & Bradley, 1985). Six

of their recommendations (pp. 252-262) relate directly to this study. These are:

1. Family support programs should be designed to empower families and persons with developmental disabilities. This principle involves recognizing families' commitments to caring for their own disabled members, encouraging family independence from the formal service system, and incorporating the views of the family and disabled person as to the design and delivery of services.
2. Family support programs should provide families with multiple service options. Just as individualized services are mandated for disabled children and adults, services for families must be individually designed to meet the unique needs of each family. The only way to fulfill the goal of individualization is to make available an array of services capable of responding to a variety of family circumstances. At the core of this array must be accessible options that allow families to care for their disabled children while still meeting their other demands. Respite care is the most obvious and underutilized component of such an array.
3. Family support programs should make greater use of cash programs. If an array of individualized services is available, then families must be provided with the resources to independently make use of them. The experience in several states has been that such cash assistance programs, available on a near-universal basis to families with severely handicapped children, are cost effective and responsive to individual needs.

4. Family support programs should make greater use of options under the Medicaid program. New Hampshire has implemented both the Community Based Waiver Program and the Model Waiver Program, but there remains much confusion about the use and effectiveness of these approaches. The potential for major national reform of Medicaid policy relative to the care of disabled children and adults is unclear. Service providers and families must be fully informed about the availability of these programs, and policy makers must seek to implement more permanent solutions.
5. A national study should be undertaken to identify the social and economic characteristics of families with members with developmental disabilities and to estimate their numbers.
6. A study should be made of sociological and demographic trends related to the family's caregiving capability. These last two recommendations are clearly applicable to New Hampshire. They also are related to the first set of policy recommendations in this chapter. In order to serve families with disabled children well, we need to know where those families are, how they are currently coping, and what their needs will be as their children grow older and move from one kind of setting to another.

Conclusion

There is a danger in social policies affecting handicapped children that their end result will be what Farber and Lewis (1975) refer to as "progressive status quoism." Analyzing provisions for parent involvement in the education of their children, Farber and Lewis call attention to policies that require a central role for parents as teachers and decision

makers. Although such policies appear to be progressive and are justifiable empirically, they have the potential to exonerate professionals of responsibility for significant change in children. If a child fails to benefit from an educational program in which his or her parent plays a central role, then the blame for failure is at least shared by, if not transfered completely to, the parent. Professionals "give up" their power and influence by sharing them with parents, but they also may give up a sense of culpability if their efforts do not lead to desired outcomes. Thus the appearance of progressive policies and practices is created, but the status quo that suppresses human development is maintained.

The situtation described in this report may be analogous. That is, social policies aimed at moving children from public institutions into less restrictive community settings are viewed as progressive and desirable. They reflect years of parent and professional advocacy and strong empirical support for the ill effects of institutional care. Yet the intent of these policies--integration of children with disabilities in social and educational mainstreams--has not been fully achieved. Fifteen years after the beginning of the deinstutionalization movement, communitization remains an elusive goal. Some observers may question whether we are practicing progressive status quoism if the consequences of the social policies of the past decade have been to move children from one environment to another without actually increasing the degree to which they have become fully participating members of the community. The resolve to transform deinstitutionalization into communitization has not yet been fully demonstrated.

This incomplete process has left children with severe handicapping conditions and their parents caught in the middle. On the one hand, we have virtually eliminated institutions as options for the placement of developmentally disabled children. On the other hand, the option of caring for children at home is limited by the lack of both formal and informal support systems for many families. Families still feel tremendously burdened and are anxious about the permanence of community-based care. Children in public schools have minimal opportunities to learn with and from their able-bodied peers. Necessary educational and therapeutic services are prescribed but not always delivered. Community living facilities are rarely family-like in size or structure.

We are not arguing that deinstitutionalization has not worked as intended. Rather we are saying that there is much progress that must be made if we are to avoid maintaining the status quo. The recommendations in this chapter are consistent with the incremental but progressive qualities that have characterized social policy reform in the United States. There is nothing revolutionary or impossible proposed here.

Some may ask the question, "So what?" If children have been completely removed from institutions, and no more are being admitted, isn't the information in this report a piece of history with no relevance for future practices? The answer to this question lies in the larger historical context of the treatment of handicapped children. There are no guarantees that social policy will remain stable and linear into the long-term future. Given the uncertainty that has marked this arena of social policy, and the powerful forces of economic and political exigencies, some future generation (perhaps the next one) will confront

the same issues, albeit in a different historical and ideological framework. Societies in all likelihood will continue to search for havens for their deviant and damaged members. Whether that search leads to the natural, safe, and autonomous environment of families in local communities or back to the contrived, impersonal environments of residential institutions is a decision in which all of us must continue to participate.

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IATROGENIC TREATMENT: THE STORY OF DANIEL MARTIN

Introduction

The story of Daniel Martin is not one that anyone in the field of human services can ignore. From the early childhood years through adolesence and into adulthood, Daniel's life has been the result of his own misfortunes, the lack of services that would enable his family to overcome Daniel's special needs, inadequate and inappropriate treatment in residential institutions, and little opportunity for movement into more normal community-based environments. We have chosen to include Daniel's story because it is representative of the worst that can occur when too few resources are made available to someone who is in such extreme need. In spite of a devoted and committed father, concerned professionals at the State School, and the best intentions of those who manage community services in Daniel's home town, his life has been neither happy nor fulfilling. In this case, we can see the dark side of being severely retarded and living in a residential institution during the 1970's.

Although Daniel is a member of Population One in this study because he left the State School while he was still in his childhood, he never lived in a normal community until he became an adult. His "community placement" was to New Hampshire Hospital for a period of four months when he was 20 years old. In 1985, after living in the two public residential institutions in New Hampshire for 21 years, Daniel moved into a group home in the community in which he was born. He was 26 years old.

Background

Daniel Martin was born in 1959. His father, John, worked at the time, as he still does, as an assembler for a local manufacturer. John had a few years of high school before he began his lifelong work. Daniel's mother, Muriel,

completed grade school and has since worked at home, caring for Daniel's older sister and Daniel until he was institutionalized. Muriel has had several boughts with mental illness, and has been hospitalized for prolonged periods of time during the most severe episodes.

Daniel's early years were marked by temper tantrums beginning when he was six months old. He was quite sick during his first year, when bronchial asthma and a high fever resulted in a period of hospitalization. He was also prone to accidents, having several serious falls involving head injuries before he was two years old. By the time he was five, his parents found it very difficult to control his temper and behavior. On the advice of their family physician and a local child guidance clinic, they sought placement of Daniel at Laconia State School. John and Muriel felt they were not capable of handling his severe behavioral problems, and his chronic bronchial illnesses also created a continuing strain on the family. There were no residential or educational alternatives in their own community.

When the parents applied for admission to LSS in 1964, the enrollment there was already over capacity. It was suggested that Daniel be temporarily placed at New Hampshire Hospital (NHH) until space at LSS became available, and this interim placement soon occurred. At NHH, Daniel became very upset. He had always been very attached to his family, and this abrupt separation and placement among older children and adults with severe behavior disorders led to more severe problems in Daniel. He lived at NHH for ten months before moving to the State School.

When Daniel moved to LSS in 1965 at six years of age, he was diagnosed as severely mentally retarded with psychotic tendencies. He was healthy, could take care of his own basic needs, and could communicate effectively with others. His only major problem seemed to be his severe tantrums. No further mention is found in the records of his bronchial condition.

Life at LSS

Soon after Daniel moved to Laconia State School, he was placed on heavy dosages of medications to reduce his oppositional and sometimes violent behaviors. The use of these medications was inconsistantly monitored due to the absence of a single physician who could oversee Daniel's treatment. During the late 1960's and throughout the 1970's, LSS had no regular physician on its staff. Local physicians from the Laconia area would rotate responsibilities at LSS on a weekly basis, so a particular physician's preference for a particular drug seemed to be what determined Daniel's type and amount of medication over this 15-year period. Daniel's medication history is revealing of the way in which some severely disruptive residents were treated during this era.

In 1965, Daniel began receiving Mellaril, an antipsychotic, and Librium, a tranquilizer. Mellaril became the primary antipsychotic drug used throughout his stay both at LSS and later at New Hampshire Hospital. In 1966, Daniel also received Phenobarbital, a sedative often used in conjunction with other drugs to control seizure disorders (which Daniel did not have), and Vistaril, a tranquilizer. Beginning in 1968, Daniel was given Thorazine, a tranquilizer, and Dexadrine, an amphetamine. By the early 1970's, he was back to Mellaril, with occasional reliance on Stelazine, an antipsychotic drug that the Food and Drug Administration classifies as ineffective in the management of behavioral complications associated with mental retardation. In 1973 and 1974, Daniel was given Thorazine, Valium, Stelazine, and Mellaril. From 1975 to 1979, he received both Mellaril and Serentil, a tranquilizer. In 1980 and 1981, Daniel was on Mellaril and Librium. In 1982, Thorazine, Haldol, an antipsychotic, and Navane, a tranquilizer, were prescribed. Daniel had a toxic reaction to the Navane, and it was shortly

discontinued. Throughout this 15-year period, these various medications were given simultaneously as well as sequentially. Some of the intake periods were as short as one week, because the physician on rotation for a particular week would often change the prescription ordered by the previous week's physician.

As early as three years after these prescriptions began, one physician wrote in Daniel's medical record, "The patient has thus far had Vistaril, Mellaril, Dexadrine, Dilantin, and Phenobarbital with no effect on behavior one way or the other because he is psychotic." One year later, another physician ordered that all medications be discontinued. One week later, a different physician, writing immediately below the previous order, prescribed Dexadrine, Mellaril, and Thorazine. The next note of concern appears eleven years later, when a physician noted possible signs of neurological damage due to prolonged use of tranquilizers.

At the same time Daniel was receiving these various drugs, his behavior remained problematic. Staff noted that Daniel became agitated and aggressive in overly stimulating, noisy, unstructured environments. In quieter, more structured, less distracting settings, his behavior improved noticeably. Staff also noted that Daniel's aggressive behavior increased if he did not see his parents on a regular basis. His clinical records throughout this period refer to lacerations and bruises as the result of his assaults on others and their assaults on him. In 1979, Daniel's arm was broken when a staff member attempted to restrain him during a fight with another resident.

The poor progress and continuing problems with behavior management prompted the LSS staff to recommend that Daniel be transferred to the state hospital in 1979 for evaluation purposes. Daniel's father agreed, and Daniel moved back to the Hospital, where he had been originally placed 14 years earlier. At the time of the placement, Daniel was described as having some

reading and writing skills, capable of feeding, dressing, and toileting himself, and able to interact positively with others if given encouragement and assistance. He also was frequently violent towards other residents or staff and occasionally damaged property, was rebellious, engaged in stereotypical behavior, and made inappropriate sexual advances. It was also suspected that he was having hallucinations. After four months at the state hospital, the staff there determined that Daniel's primary diagnosis should remain mental retardation rather than pychosis, and he was sent back to LSS with a recommendation that one-to-one supervision be made available in order to reduce the need for over-medication. No changes in his behavior were noted as a result of this brief placement outside of LSS.

Daniel's family kept in close contact with him during his residency at LSS and the state hospital. Both parents visited him at LSS monthly throughout the 19 years he lived there. They also brought him home for brief periods several times each year. Daniel's father, John, was especially involved in overseeing his care. John became an active member of the LSS chapter of the Association for Retarded Citizens, and during the period of litigation in the late 1970's began to take a more active role in the decisions that affected Daniel's treatment.

John's major concerns from the late 1970's to the mid-1980's focussed on Daniel's physical safety and the heavy reliance on medications. John became increasingly concerned after 1980 when he observed that Daniel was acting very withdrawn and drowsy during his visits. He frequently contacted LSS staff to question the use of the medications. These contacts soon resulted in his being labeled as a nuisance by the staff. They felt that he was overreacting and was meddling in an area he knew nothing about.

In 1982, Daniel began to regurgitate soon after his meals. John viewed this as a sign of over-medication (Thorazine was the primary drug at the

time); the staff interpreted the problem as purely behavioral. The result was a behavioral program that consisted of making Daniel clean up his own vomit and then placing him in time out. The Thorazine dose was also reduced because of extreme daytime drowsiness. A drop in the frequency of regurgitation was soon noted.

For a variety of reasons, Daniel received little formal programming while he was a resident of LSS. Partly due to his aggressive behaviors, partly due to the heavy medications, partly due to the fact that he was essentially intact and healthy, and partly because they simply were not available, Daniel did not participate in many activities that would have prepared him for life in the community. He did join other residents on regular trips into the city of Laconia after 1980, where his behavior was noted to be much better than it was at LSS. The one-to-one supervision recommended by the Hospital staff did not occur.

Under the pressure of the court order, LSS staff began to project community placement for Daniel. John Martin was strongly in favor of such a placement, but only if it could meet Daniel's needs and if it meant a reduction in the amount of medication he used. In late 1982, the LSS staff developed a plan for eventual community placement, and in early 1983, a case manager from Daniel's home community was assigned to search for an appropriate residence with adequate services.

The Transition

Daniel's return home took a major detour. Because of his persistent behavior problems, it was again recommended that he be placed at New Hampshire Hospital for evaluation purposes. So in the fall of 1983, Daniel moved to the Medical Services Building at NHH. He was assigned to the Tobey Building, which is intended for mentally retarded psychiatric residents, but lack of

available space there resulted in the temporary residence in the infirmary. At the time of this move, Daniel had begun to show signs of a seizure disorder that his case manager believed was partly due to the prolonged use of psychotropic medications. He was subsequently diagnosed as having tardive dyskinesia as well as active tuberculosis.

While at the Hospital, Daniel received regular medical attention and counseling. No educational or vocational training was provided other than behavior modification. Case management was provided both by the developmental services agency in his home community and by the Hospital social services staff. Recreation activities were also available. Due to the temporary nature of his placement there, and to lack of available and appropriate staff, no specific programming was provided that would prepare Daniel for the eventual move into a less restrictive environment.

During this period, the local developmental services agency was attempting to create a small group home that would be capable of meeting the needs of people such as Daniel who had severe behavioral disorders. The agency first targeted June of 1983 as the time at which such a facility would open. Due to lack of adequate state funding and the need to rapidly develop other community-based programs, the intensive behavior shaping group home was delayed. The temporary stay at NHH turned into a 20-month residency.

In mid-1985, a private contractor specializing in the development of community residences for people with severe mental retardation was hired by the developmental services agency to create such a facility. Daniel was identified as one of the first people the agency wished to place in this privately-run home. Even before such a home was completed, the private contractor, the Institute for Professional Practice, made arrangements for Daniel to live in a supervised apartment in his home town. He moved into the apartment in July, and then moved into the completed home in October, 1985.

The new home has four other residents with needs similar to Daniel's. Here, Daniel participates in regular educational programs aimed at reducing his inappropriate behaviors and enabling him to function in the community with minimal supervision. He has made the adjustment to this radically different environment quite well. His parents report that they are very pleased with the group home, and that Daniel seems to like it. They visit him three times a week, and bring him to their home for occasional overnight stays. In 1985, Daniel spent Thanksgiving at his parents' home for the first time since he was four years old.

Future Plans

It is too early at this point to predict what will happen to Daniel over the next few years. Short-term goals emphasize reducing the medication he receives to a minimal level while providing a structured and stimulating environment. The ability to hold down a regular job and more fully participate in community life will depend on the degree to which Daniel's behavior becomes less aggressive. Already there are hopeful signs that his new home, more contact with his family, and frequent opportunities to function in community life are leading to more normal behaviors. The time needed for Daniel to learn how to interact appropriately with other people, especially with women who he previously only knew as institutional staff or fellow residents, will be considerable. Having never had these opportunities, it is very difficult to know where Daniel's true potential lies, and to what degree a lifelong history of institutionalization will limit the development of that potential. But Daniel is still young and has a caring family closeby. These will be his most important assets as he begins a new life.

"RAMPS ARE NOT ENOUGH": THE STORY OF KERRY GAGNON

Introduction

Kerry Gagnon's favorite time is in the morning, when she usually wakes early and spends a quiet period with someone who can help her put on her make-up and perfume. She especially likes to have her hair fixed neatly before the day begins. Her friendly manner, quick smile, and engaging personality mean that others don't mind helping with this early morning routine.

Kerry lives in a group home with several other people who have severe mental and physical disabilities. She stands out among her peers as "the belle of the ball," as the house manager puts it, because of her sociability and her bright mind. Although she is unable to speak or move from one place to another without assistance, Kerry obviously has many important qualities valued in any young woman. She has a strong self concept, is cooperative with her professional caregivers, and is extremely curious about the world around her. She is happy about living at this home, where she moved in December of 1984. Prior to that time, Kerry had lived at Laconia State School for twelve years.

Kerry's Background

Kerry was born in the fall of 1966. Her birth was uncomplicated, and she and her mother came home from the hospital soon after the birth to join her older brother and her father. She and her family lived in Massachusetts at the time of her birth.

At six months of age, Kerry's mother began to be concerned about her daughter's development. Mrs. Gagnon noticed that Kerry had difficulty sitting and rolling, and she observed some difficulty in using one side of her body as well as an unusual tightness in the hand on that side. By 17 months of age,

Kerry had experienced several seizures, some of which lasted as long as 20 to 30 minutes. Mrs. Gagnon sought help for Kerry at an urban hospital. There Kerry was diagnosed as having microcephaly, spastic diplegia, and significantly delayed development. Her development was equivalent to that of a six-month old infant, and there were no signs that her development was progressing beyond that level. Kerry's parents sought additional help over the next several months, but there were no programs available in the Manchester area, where the family had recently moved.

After exhausting the available resources in their local community, and realizing there was no one who could help them in Manchester, Mr. and Mrs. Gagnon brought Kerry to the Laconia State School for an evaluation. At the time, LSS was the only place where such comprehensive evaluations were offerred in New Hampshire. Kerry stayed at LSS for two weeks. At the end of this period she returned home with an evaluation report that recommended physical therapy and continued observation. As there were no qualified physical therapists in Manchester who could provide the recommended treatment, Kerry returned to LSS every few months for a brief period of therapy. She also stayed at LSS for several weeks at a time when her parents went away on summer vacations.

In the summer of 1972, Mrs. Gagnon had surgery that prohibited her from lifting Kerry. This limitation quickly became a major factor in Kerry's ability to remain at home with her family. Mrs. Gagnon's physician recommended that Kerry be admitted to LSS as there were no services in the local area that could meet her needs and her continued presence at home would create an impossible burden on her family. At the time of her admission in July of that year, Mrs. Gagnon wrote to the LSS social worker,

> I do not know if this is best but under professional advice, I am willing to give it a try if it will in any way help my daughter and make her life happier. I understand that I will be kept well informed as to her progress and needs and can see her often.

After her admission, Kerry was again evaluated. It was apparent from the evaluation that she could not walk, talk, or use the toilet. Her measured IQ was below 20, and the diagnosis of profound retardation was assigned to her.

Life at LSS

In spite of this pessimistic diagnosis, the staff at LSS recognized that Kerry's severe physical disabilities were the major source of her limitations. Her intellectual capacities were judged to be significantly more advanced than her physical and self-help skills. The staff at King Building, where Kerry spent most of her time while living at LSS, decided to try to enhance Kerry's intellectual capacities as much as possible. She was described by her care-givers as an "extremely bright, personable, and oriented young woman who enjoys social interactions." Kerry understood anything that was said to her, although she remained unable to speak due to the severe limitations caused by the cerebral palsy. She was able to communicate her thoughts and emotions through laughter, crying, pouting, and refusing to cooperate. She also could point to things she wanted or places she wanted to go. She clearly had a strong personality and possessed many abilities within her damaged body.

Because of her outgoing personality and her intellectual strengths, staff at LSS concentrated their efforts on Kerry moreso than most of the other residents in King Building. Over the years, she received occupational, physical, and speech therapy. She was taught some basic signs and gestures so she could express her wishes, and she was given a simple communication board to expand her vocabulary. She learned to help others get her dressed, feed herself with special utensils and dishes, and maneuver her electric wheelchair. She continued to be dependent on others for bathing, toothbrushing, and toileting.

During her stay at LSS, Kerry's family was closely involved in her care. Although her parents were divorced shortly after her initial admission, and her mother subsequently moved away, her father and stepmother remained in regular contact with Kerry and the staff at King Building. They visited Kerry about five times a year during this 12-year period. During the summers of 1982 and 1983, Kerry went to summer camp.

Throughout her residency, Kerry was seen as a good candidate for community placement. In late 1978, Kerry became one of the first LSS residents to be assigned a community case manager whose job was to advocate on her behalf and seek an appropriate community residence. The appointment of a case manager for Kerry occurred because her family happened to live in a region where one of the first experimental case management systems in New Hampshire was established. The case manager quickly began an active search for a foster home or group home that could meet her needs. A target date of June 30, 1979 was selected as the time at which Kerry would leave LSS and return to life in the community.

Kerry's father and mother did not initially approve of the idea of community placement. They both felt that Kerry was well cared for at LSS, and that there was no suitable community program available that could meet her needs. Although the case manager found foster parents who were willing to care for Kerry and who lived close to Kerry's father and stepmother, Mr. Gagnon objected to the placement on the grounds that Kerry was happy at LSS and had grown attached to the "foster grandmother" who visited with Kerry on a regular basis in King Building. Mr. Gagnon said at the time, "If we take her from this environment and place her somewhere different, she will be unhappy and this is the last thing I want is to make my daughter unhappy." He wanted more time to think about the idea of community placement, "as it is a big decision to make." Mr. Gagnon's resistance to the idea of community placement

did not change over the next few years, and active efforts to locate an appropriate home outside of LSS were not pursued. However, the pressure of the 1981 court order, the continuing belief on the part of LSS staff that Kerry would benefit from community placement, and an emerging confidence on the part of her father that such a move would be for the better eventually led to more concrete plans for community placement.

The Plan

In the summer of 1984, a plan was developed by a team that included Kerry's parents, teachers, therapists, case manager, and LSS support staff. The resulting Individual Service Plan (ISP) outlined Kerry's needs and described in detail the type of residential and educational program that should be provided in the community. The ISP established October 1 as the date on which the transition from LSS back to the community should occur. In order to assure success in the transition, it was recommended that Kerry be gradually moved out. She was to visit appropriate group homes several times before a final decision was made and the move became permanent.

The first home found by Kerry's case manager was felt to be inappropriate by the LSS staff. It was located in an isolated rural community and was not designed to accommodate Kerry's wheelchair. The other residents were all geriatric clients who would "not be able to take Kerry's loud music" according to her LSS social worker. Subsequently, this home was rejected as a possiblity for Kerry. During September and October, several other possible placements were considered, but none were believed to be capable of meeting Kerry's needs. At LSS, direct care staff were assigned additional clients in anticipation of Kerry's departure, which was not forthcoming. They described her status as "in limbo" during this period. Although they wanted to continue appropriate programming for Kerry, particularly with respect to her communica-

tion skills, the staff was unable to plan relevant activities without knowing where she would end up or when. They also expressed frustration at not being informed of changes in plans for Kerry.

In October, a new home was located that would accommodate Kerry's wheelchair and where the other residents were closer to Kerry's age. Kerry's father approved of this placement, and plans were made to proceed with the move. An opening at the home was anticipated in the near future when one of the current residents moved out. This became a major problem as Kerry's placement was continually deferred to a later date due to delays in moving the current resident.

In early November, a transition plan was created. LSS staff met with the group home staff to discuss Kerry's needs and ways to provide continuity in her programming. Kerry's parents met with her case manager to also discuss the best methods for assuring a smooth transition. Services that would be required in the community home included physical therapy, speech therapy, wheelchair maintenance, and nursing services. Not all of these were available at the home, so additional work was necessary before the move. A two-week transition period was designed to allow Kerry the opportunity to visit the home, have dinner with the other residents, spend a night, and visit her proposed educational program in a nearby city.

During these trial visits, Kerry's father came to the group home to welcome and reassure her. She cried on the first day when she was separated from her closest friends on the LSS staff, but soon showed signs of accepting the pending change. Her social worker at LSS described her return from one visit, when Kerry "started packing her clothes." She understood what was planned, and was eager to make the move.

Over the next six weeks, there were further delays. On several occasions, Kerry was about to leave LSS for a visit to the group home but

no one came to pick her up at the agreed-upon time. At one point, the group home staff requested that LSS keep Kerry indefinitely as the group home was understaffed. The group home staff also requested a 30-day notice prior to the final move. During this period, Kerry said good-bye to her friends at LSS three different times anticipating her final departure. The uncertainty began to affect Kerry, and she had several toileting accidents and screamed in anger at the staff. On the other hand, her father saw the value of prolonging the transition process as it gave Kerry more opportunities to visit the home and get used to her new environment.

Finally, on December 18, 1984, over five years after the initial decision to place Kerry in a more normal environment, she made a permanent move to a group home within close driving distance of her father, sixty miles away from LSS, and about 15 miles away from the private school she was to begin attending. She was 18 years old.

Life in the Community

Kerry expressed much happiness about her new home. She made the adjustment easily, developed friendships quickly with the staff at the home, and began a more normal life that included taking care of her own clothes, helping with meals, going swimming, eating in restaurants, shopping at malls, and listening to Michael Jackson records. She has regular visits to a dentist, physician, gynecologist, and optometrist. The major shortcoming of this new life is the lack of opportunities to interact with others her own age. Although the other residents at the group home are also young adults, they have such severe intellectual and social limitations that Kerry is unable to benefit from their presence. She is unable to communicate with them, and "rarely knows the other clients are around" according to a staff member.

Kerry attends school daily at a private development center. She is enrolled in the Teen Development Class with other young adults from 17 to 20 years old. She enjoys going to school, is well liked by the staff and other students, and generally works hard on her educational program. She receives individual instruction for much of the day in areas of self-feeding, physical therapy (which she also receives at home), social skills, communication, personal care, and pre-vocational skills. She is also learning to read. The school takes Kerry and her classmates swimming, bowling, and on other community outings regularly.

One of the biggest problems that has occurred in this transition is maintenance of Kerry's wheelchair. As hers is in poor condition, it is not satisfactory for the frequent trips she takes from home to school and out into the community. Another major problem has been in developing an appropriate educational program that fits her specific needs. Staff at the group home are concerned particularly that the communication program at school is not well designed and not easy for Kerry to use.

During this early period of community adjustment, Kerry has been fortunate to have a family that has provided much affection and protection for her. Shortly after her move to the group home, Kerry's natural mother traveled a considerable distance to visit her, the first direct contact in several years. Kerry has pictures of her natural mother and her brother at her bedside in her new home.

Mr. Gagnon is very pleased with the move into the community. He visits Kerry at least monthly and talks at length with her and the other residents. Kerry's stepmother seems to be more anxious about the stability of the placement, and worries that Kerry will have to move into her and her husband's home if the placement should somehow not succeed.

Future Plans

When Kerry becomes 21 years old, her educational program will cease. Her severe physical limitations and lack of vocational training over the past 12 years make gainful employment highly doubtful. She will require continued therapy to assure maximum mobility and communication skills. The group home staff hope she can move into another group home with fewer people who have abilities more similar to Kerry's.

Perhaps the greatest area of need in Kerry's future, and the one that is hardest to meet, is not to change Kerry, but to change the community in which she lives so it is better able to accommodate her needs and the needs of others like her. As one staff member at her present home says, "The community needs to be aware, involved, and understanding. In order for people like Kerry to get the most out of community life, the community has to adapt to them and accept them. Ramps, rails, and elevators are not enough."

STAYING CLOSE TO HOME: THE STORY OF CHERYL BONAVENTURE

Introduction

Cheryl Bonaventure is a 17 year old woman who has lived in Laconia, New Hampshire all of her life. For the first 11 years, she lived at home with her family. Then, because of her multiple disabilities, and the resulting stress faced by her parents, she was admitted to Laconia State School. She remained there for five years, all the while continuing to attend the public school in her home community. Cheryl left the State School in June of 1984, and presently lives with Joan, a woman who works as the teacher's aide in Cheryl's classroom. Cheryl is able to visit with her family every weekend. This story is about the ability of a family to stay close, both physically and emotionally, during and after the institutionalization of one of its members.

Cheryl's Background

Cheryl's handicapping conditions were obvious immediately after her birth in 1967. She was subsequently diagnosed as having a convulsive disorder, cerebral palsy, vision and hearing impairments, and a communication disorder. Since early childhood, she has been classified as severely mentally retarded. In the early years of Cheryl's life, her mother had no one to talk to about Cheryl's needs, and was unaware of how to meet those needs. Mrs. Bonaventure remained at home for seven years to provide full time care for Cheryl. There was no educational programming, domestic help, or respite care available. Cheryl's parents had no knowledge about how to meet her special needs. Her mother had

graduated from high school, and her father graduated from college, but, like most people, there was nothing in their background to prepare them for the demands created by caring for a severely disabled child.

When Cheryl was eight years old, she began attending a day care center organized by a group of parents. There was no special education at the day care, but the opportunity to be with other children, and the relief for her mother from constant care, were important benefits of the program. It was at this time that the family's pediatrician began to provide specific advice about Cheryl's needs, the first such guidance since her birth.

In the Fall of 1975, Cheryl was enrolled in a public elementary school in Laconia, in one of the first public school programs in New Hampshire for children with severe handicapping conditions. The Bonaventures relied heavily on the school teachers to provide them with information about Cheryl's needs and to recommend appropriate programming. Mrs. Bonaventure admits that at this time she and the other family members were "not looking at things realistically," and had no idea of Cheryl's limitations or abilities. However, the assistance sought from Cheryl's teacher proved to be less than optimal, and the Bonaventures found themselves joining with other parents of children in the class to express their concerns about the teacher's abilities and the quality of the educational program.

During this period, there was no physical therapy available in the school. Cheryl's mother took her weekly to the local hospital. There was also no guarantee that other educational or related services would be made available. It was not until 1978, when P.L. 94-142 was fully implemented and the New Hampshire special education law was strengthened, that Cheryl's program became more comprehensive.

Mrs. Bonaventure described these early years of special education:

> We weren't aware we had any rights. Each spring we'd have an IEP meeting, but we never knew who was who and what was going on. I found out you never got anything. I learned that I could get more for Cheryl if I asked for it, if I demanded it. No one ever offered us anything.

Beginning in 1978, teachers at Cheryl's school began to inform parents of their rights. They provided literature describing the mandates in P.L. 94-142 and the rights of parents to participate in educational decision making. There were noticeable changes in the quality and scope of services after this point, according to Cheryl's mother.

However, these positive changes in the availability of services did not compensate for the poor quality of the teaching Cheryl was receiving. When Cheryl was 11, she was expelled from school because her teacher was unable to manage Cheryl's difficult behaviors. She spent the next six weeks at home with no educational services or therapy. Mrs. Bonaventure consulted with her pediatrician, who argued strongly for Cheryl's return to school.

These eleven years were beginning to take their toll on Cheryl's family, particularly her mother. It had taken Cheryl eight years to learn how to walk and use a toilet, her language abilities were very limited (her hearing loss was not discovered until she was an adolescent), and there was almost no help offered by Mrs. Bonaventure's mother or other relatives who lived close by. Cheryl's parents felt isolated, tired, and angry at the lack of support available. Although Mr. Bonaventure was an important source of support to his wife, his job demanded that he commute about 120 miles, thus keeping him out of the home over 12 hours a day. These factors led to a difficult but apparantly unavoidable decision.

Life at LSS and in the Community

After Cheryl was expelled from school, her parents began to consider placement at Laconia State School. In 1978, when she was 11 years old, Cheryl was admitted to LSS because, her mother says, the family was at the end of its rope, there was no assistance in Cheryl's care at home, there were no other residential arrangements available in the community, including respite care, and the family felt that it was time to try "the last resort."

Cheryl's placement at LSS was unique in that she could continue to attend school in her home community. The school accepted her back when she entered LSS, with the understanding that LSS staff would provide on-site consultation to help with Cheryl's behavioral needs. This assistance was provided daily for several months. During this time, Cheryl went home to live with her family on most weekends, and lived at home during school vacations.

Although LSS staff provided assistance to the public school, there was very little programming available at the institution to supplement the school program. Cheryl needed consistent follow-up on behavioral programs when she was not in school. She also needed monitoring to be sure she wore her hearing aids and glasses, as well as assistance in improving her communication abilities. None of this happened at the institution, according to Mrs. Bonaventure.

While at LSS, Cheryl did not develop social relationships with the other residents. Because she spent so little time there during the day and on weekends, she was relatively isolated. She was moved frequently from one building to another, and was often placed with other residents the same age but who were functioning at much lower levels. She

occasionally was attacked by other residents, and was unable to defend herself due to her physical and language limitations.

In school, limited progress was occurring. Cheryl benefitted from the opportunity to socialize with the other children in her class, and she made gains in her ability to communicate. She learned a few basic self-helf skills such as toilet training and toothbrushing. Lack of trained staff limited the amount of additional skills Cheryl learned.

In 1983, when Cheryl was 15, her teachers suggested that she was ready to move up to the Junior High School. They were concerned about Cheryl's need to be with children her own age and they felt the Junior High program would better meet her educational needs. Mrs. Bonaventure was very leery of this move. She said, "I feared sending her there, not knowing how the other kids would treat her. They seemed much older. It was hard for me to accept the fact that she had to grow up."

Despite her initial hesitations, Mrs. Bonaventure soon realized that Cheryl was happier in the new program. Cheryl continued to live at LSS on weeknights and attend public school during the day. The Junior High program was better able to meet her individual needs, and provided many opportunities to meet other teenagers of varying skill levels. The curriculum included such areas as learning to tell time, money management, appropriate social skills, following a schedule, carrying out job orders, and participating in a basis vocational training program. Her individual program stressed both sign language and improved oral speech.

Coming Back to the Community Full-Time

Beginning in 1982, shortly after the federal court order was issued requiring community placement of most of the LSS residents, LSS staff began to plan for Cheryl's return home. However, her family did not feel

they could accept Cheryl back home on a full-time basis. The next two years were spent searching for an appropriate placement in the community, near to her school and family. In the end, it was one of Cheryl's teachers, a single woman, who offered to serve as a "shared home provider." Mrs. Bonaventure was very pleased with this arrangement. She said, "Cheryl was one of the lucky ones. We had to wait a long time, but we were very fortunate that this happened." In 1984, Cheryl moved into Joan's house and continued to attend school at the Junior High. She also continued to see her family on a weekly basis.

One of the most valuable aspects of this arrangement was the continuity in educational programming. Because of Joan's direct involvement in Cheryl's school program, there was consistent follow through on all of Cheryl's individual programs. She could practice her new communication skills at home, and carry out the self-help program under the guidance of a trained professional who could also offer love and affection. In her new home, Cheryl had responsibility for preparing her own breakfast, making her own bed, dressing herself, and generally being as independent as possible.

At school, the program continued to improve. As of 1985, Cheryl was receiving occupational and speech therapy, peer tutoring, orientation and mobility training, and behavioral therapy. Her social skills became sources of strength, as she acquired a good sense of humor, improved in her ability to communicate, and learned to express her feelings more appropriately.

It should be noted that these services did not automatically become available. After the IEP was developed, the prescribed mobility training was not provided. Cheryl's parents reminded the school district that this service was included in the IEP, and must be made available.

Arrangements were soon made to provide the service. "I wonder if they would have done anything if I hadn't spoken up," said Mrs. Bonaventure.

As with other children described in this study, the one area at school that was not well developed was vocational training. Cheryl's teacher is opposed to preparing Cheryl and other severely handicapped children for life in a sheltered workshop, but the necessary training for work in a more competitive setting is not yet available. A vocational assessment had been completed just prior to our interviews with Cheryl's teacher and family. It is hoped that this will lead to a concrete plan to prepare Cheryl for independent employment after she completes school.

Future Plans

Cheryl's present residential arrangement is seen as a temporary one, to be phased out as Cheryl completes her formal schooling. In interviews with Mrs. Bonaventure and Cheryl's teacher, a future based on group home or shared home living options was projected. Both people agreed that a group home would be a positive step in Cheryl's development as an adult. Mrs. Bonaventure commented, "I think group homes are fine as long as they are supervised, and I know Cheryl will always need supervision. She will never be able to be left alone; and it is much better than an institution."

Typical of their close involvement in Cheryl's life, and in the lives of other people with mental retardation, both parents have become active in the improvement of services in the Laconia region. Cheryl's father is on the Board of Directors of the regional agency which oversees the development of group homes in the area. Her mother has become active in a group of parents organizing fund raising for community recreation programs. Both parents are very concerned about community awareness of

the strengths, capabilities, and needs of Cheryl and others like her. Mrs. Bonaventure stated,

> I wish people would deal with them as people, and not just as what they see on the outside. People really need to be educated about mentally disabled people. They're not going to harm you and their desires are the same as yours and mine. That's the whole thing. That's what it is. They need to be educated.

Although plans for residential arrangements are fairly concrete, further training and work opportunities are less apparent. Mrs. Bonaventure pointed out that, "Once these people turn 21, the programs aren't there." Her desires for Cheryl include a job, but she is skeptical of the possibilities.

> If there are no jobs, what can you do? What do you do when you are 21 years old? If you are severely mentally disabled, the chances don't look good in New Hampshire.

Cheryl's parents have a specific dream for their daughter. They would like to create a group home with other parents of severely handicapped children. They are aware of the time and expense involved in such a project, but their energies and commitment seem endless. They are realistic people, and they recognize their own limitations. Their initial decision to place Cheryl in LSS was based on the realization that they could not handle her extraordinary needs without extraordinary help, which was simply not available from either family or professionals in the mid-1970s. Now such help is available, although not without constant efforts from parents and advocates.

Cheryl has been more fortunate than many children in her circumstances. She lived with a family that cared deeply about her and went to great lengths to see that she received the services she needed. When the family could no longer care for her in their own home, she continued to have the chance to see them regularly and to attend a public

school, even while living in the institution. She was able to return to the community when a caring and competent teacher took an interest in her and sacrificed her own privacy to create a more independent life for Cheryl.

Her experiences provide a vivid illustration of the evolution in services that took place in the late 1970s and early 1980s. Her community progressed from a point of virtually no services, to services of poor quality, to services capable of responding to individual needs. These changes closely paralleled the implementation of legislation and court orders guaranteeing a free appropriate public education in the least restrictive environment. There is still much work to be done, especially in the area of residential and employment services, but the evolutionary trend is apparent in this example. The key to Cheryl's success has been the interaction of a committed family with caring professionals, working collaboratively within the context of an improving service delivery system.

OUT ON HER OWN: THE STORY OF GG LAWSON

Introduction

GG Lawson, now in her early 30's, works at a prestigious preparatory school in New Hampshire. The school is located about 25 miles from her parents and about 50 miles from her closest sister. She lives independently in campus housing in a small dorm room with space for a bed, a dresser, a desk, and a chair. She eats with her fellow staff in the common kitchen off the main student dining room, where she works as a member of the maintenance crew.

GG represents the oldest cohort of those people included in this study. She lived at Laconia State School between 1965 and 1971. She left at a time when there were no community services available, and she became an adult before the implementation of P.L. 94-142. GG has been diagnosed as moderately mentally retarded (her mother was told, "GG is trainable but not educable"), but she has been capable of independent living since her late teens. She has had occasional difficulties in making good decisions, and she has benefitted from the guidance and support of her sister and mother.

Prior to coming to the prep school, GG had been unemployed for two years, requiring that she live at home in order to survive financially. But home life was not satisfying to her, particularly because her 13-year old brother teased her about her obesity and her "slowness." She explained in an interview, "I know I'm slow, but that's no reason to tease me." She prefers to live on her own, and has been able to do so as long as there were jobs that provided her with the necessary means.

GG has worked for 13 out of the past 15 years. She enjoys her current job tremendously. She says,

> The kids really like me. I went to one of their dances. Sometimes I go to their basketball games. They always say, 'Hi GG! Howya doin?'

GG was able to speak articulately about her life and hopes. She is an affable young woman who understands her own limitations and accomplishments. She makes new friends easily. GG is a prime example of someone with mimimum disabilities who today would remain at home in a local school program rather than live in an institution. We might say that GG was born before her time.

GG's Background

GG's parents, Geraldine and Dwayne, were 23 and 26, respectively, when their third child, GG, was born. Both parents had some technical training after high school. Dwayne owns an auto repair shop and Geraldine has worked as a clerk and produce manager in a supermarket. GG was one of six children, two boys and four girls.

GG's early development was unremarkable except she was very delayed in the onset of spoken language. At age five, in 1958, her parents took her for a hearing test to determine the cause of her delayed language. The results of the test were negative. There was no suspicion of mental retardation, although her teachers in primary school described her as a "slow" child. There were frequent conferences between parents and teachers to determine how to help GG, but no concrete action was taken. She was promoted each year, but by the end of fourth grade she was viewed as an "unhappy and lonely" child, according to her mother.

A friend of the family, who happened to be a doctor at New Hampshire Hospital, suggested that GG be given an educational evaluation when she

was 10 years old. The testing at the Child Guidance Clinic resulted in the diagnosis of moderate retardation. Professionals at the Clinic recommended that GG be sent to Laconia State School for training.

Life at LSS

GG was almost 12 years old when her mother and father brought her to the administration building at LSS. Admission took place on the recommendation of the Clinic, GG's elementary school, and, as was routinely done, the probate court. Dwayne cried in the car on the way home, grieving for his child and himself, even though he strongly believed that LSS was the best place for her training.

After the required initial period of separation and no contact between child and family, regular visits began. GG's oldest sister described for us GG's program and the family's involvement during this period:

> She was moved into this cottage program, which, at the time, was this fantastic program. It was like a home situation. They had nice rooms and they had a dining room like at home and they had house parents. It was so different than an institution. It was really a nice set-up and we'd go and visit her on weekends.
>
> When we saw how happy she was--that she was beginning to blossom out there and come into her own--we really felt better about it. You know, I think that was important, that part. And we all went. That was a big thing, to go to Laconia. We'd go up and visit GG. We were very interested in her progress, in how she was doing. Sometimes my Dad wouldn't be able to go because he was working, but my Mom would go and all of us kids that were home. There were six of us, and we were all real close. Lots of times my grandmother would go. And we'd take a picnic lunch and we'd go up, pick up GG, and go out for the day. Or we'd bring her home. She got to the point she could come home on weekends.
>
> I'd say [we went up] at least two or three weekends a month. We went up quite frequently in the beginning, 'cause she really needed that. She really needed family contact.

Life at the State School was unremarkable for GG. She participated in the domestic training program in her cottage, which consisted of

helping with laundry, meal preparation, and so on. She attended a summer camp program for residents of LSS for four summers. As was the case with other residential records we reviewed from this time period, there was little detail about GG's daily life or treatment programs. She seems to have gotten along well with the other residents and staff.

Life in the Community

After five years in the institution, when GG was almost seventeen, arrangements were made for her to participate in a residential vocational program in housekeeping at Crotched Mountain Rehabilitation Center. The program did not begin until the Fall of 1971, so GG lived at home during the summer months after her discharge. GG's return home for the summer created no special problems for her family. Her sister told us that GG's presence at home was "just like the rest of the kids" who were on summer vacation.

The Crotched Mountain program was designed to provide training in housecleaning skills. GG's mother Geraldine was very pleased with the program. She feels that GG received close personal attention and guidance which led to an independent, self-supporting life. The program culminated in job placement, and GG began a ten-year stint as a housekeeper at Clover Nursing Home upon her graduation. During this time, GG lived in an apartment in the nursing home.

Two events occurred during this time period that illustrate the potential pitfalls of living independently. These events could have happened to any young adult living on his or her own for the first time, and do not necessarily reflect common experiences of people who are labeled retarded and who happen to be living alone.

Future Needs

GG's youngest sister summarized the family's assessment of GG's past and future:

> The ultimate, deluxe situation would be that she could live alone or with other individuals a lot like herself, and have someone that could check in on her periodically. Somebody that she would truly talk to. Somebody that would make sure that she was getting along well financially. See, the thing is with GG is that (I know this might sound like a shuckoff to somebody else--let somebody else worry about her) but GG, I think, gets resentful with us as a family because she thinks we're interfering. She needs an impartial person, a mature person.
>
> She might say that when she was [living at the nursing home] running with a loose crowd, that she was happy, but she wasn't. You know, I could tell that. There was something in her voice, in the way she acted. She just wasn't happy. And now she is. She's got a life. She's got something she can talk about. She's saving money. She just feels a lot better about herself and that's really important.
>
> And I don't think she should be shunted away to some corner of the world where you put these people together.

Several years after she moved to the nursing home, GG's sister moved in with her because she had recently had to relocate to the Manchester area and needed an inexpensive place to stay until she could rent her own apartment. One day soon after moving in with GG, her sister arrived home and noticed a bill from Mastercard addressed to GG. She described the incident:

> I found a Mastercard bill in the mail addressed to GG and I opened it, which I normally would not have done except that I knew this bill was serious business. She had $800 worth of bills racked up on it! I asked her how she got the card, and she said, "I went down and they gave it to me." In her mind, that's how easy it was. And after talking to the bank, it was just about that easy.
>
> I explained to the credit manager, "I don't know how she got this card. The only thing that's her writing on this application is her signature." And he said, "Well, a lot of people don't write that well and they have the girls make them out." I asked him, "What did she use for references?" The bank had used a corner market that she had used to charge stuff at. And I just looked at him and said, "That's all it takes?" He said, "Well, she's been at her job for seven years." I said, "That's enough? You work at a job where you probably just make the cost of living increase every year for a pay raise and you have credit at a corner market that probably keeps their accounts on the back of a brown paper bag and you take that as someone who is good to dish out a credit card to? I'll be in touch with you. In the meantime, don't give her a loan or anything."

It turned out that GG's friends had "helped" GG enjoy her new Mastercard privileges. Most of the bills were from restaurants and bars in the neighborhood.

The second event was more traumatic for GG. While she was living at the nursing home, she became pregnant. Her parents and sisters gave her much support during the pregnancy, but they believed there was no choice but to place GG's baby in an adoptive home. GG told us in an interview,

> My parents said it would be better to give her up, where she'd have a good home. I couldn't take care of her. I have a boyfriend now. He wants to get married, but I'm taking my time.

> He was my first friend when I came [to the prep school]. He showed me around so I didn't feel lonely.

After the birth and adoption, GG's parents arranged for her sterilization.

Geraldine feels there was too little support and guidance for GG after her release from the institution. She would have preferred that GG live in a group home, but none were available in the early and mid-1970s for someone in GG's circumstances. GG's parents assumed responsibility for her expenses during this time. They paid for medical treatments, dental bills, glasses, and insurance, and they fought with the bank over the credit card incident. They wanted case management for GG, but none was available.

During the two-year gap in employment between the nursing home position and her current job at the prep school, GG played a key role in her family. She lived at home during this time, although her mother would have preferred that GG live in a group home to receive some guidance while still living as independently as possible. However, her presence in the home was beneficial in many ways. When her grandmother became ill and housebound, GG became the mainstay in the family. She took care of her grandmother, including making sure that she took her medicines at the proper times, preparing meals, doing the laundry, and providing close companionship in the last months of her grandmother's life. The skills she had acquired at the nursing home became crucial for her whole family. GG's mother and sisters remembered her courage and fortitude with a deep sense of gratitude and pride.